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The Lived Experiences of Black Women with Hysterectomy for Benign Fibroids

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Walden University
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Abstract

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MPH, Florida International University, 1995

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Black women are more likely than women of any other race in the United States to undergo an abdominal hysterectomy instead of a less invasive and less damaging laparoscopic or robotic procedure for benign fibroids. Although Black women are the population most disparately affected by benign fibroids, as evidenced by higher morbidity and mortality rates due to complications, they are often excluded in clinical research. The purpose of this qualitative phenomenological study was to explore the lived experiences of Black women who decided to undergo an invasive abdominal hysterectomy for benign fibroids. Semistructured interviews were conducted with 14 Black women, who were selected via purposeful sampling. The socioecological and health belief models provided a theoretical framework for understanding participants' decision-making. Hand coding and NVivo software were used to analyze the data. The eight emergent themes describe what treatment options participants were given, how much they knew about alternatives, and what influenced their treatment decisions (i.e., the desire to have children, access to social supports, the severity of symptoms, or family history of cancer). The findings illustrate the emotional stress participants experienced before surgery; the lack of knowledge they had about postsurgical effects; and, rarely mentioned in the research, the postsurgical psychosocial impacts they experienced. The study may contribute to positive social change by highlighting the need for (a) education programs targeted to Black women about minimally invasive treatment options and (b) more research about the use of counseling to improve the psychosocial impacts for women who had an abdominal hysterectomy.

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Dedication

I thank God for strength, guidance, and protection and for preserving my life so that I can experience this triumphant moment. The journey was not easy. I dedicate this dissertation to the memory of my mother, the late Mrs. Constance E. Jackson, and my father, the late Mr. Anthon A. Jackson Sr. I thank you for the strong character, morals, values, tenacity, and faith in God that you demonstrated throughout your lives. Thank you for instilling those values and stressing the importance of education. I thank God for my soulmate, protector, chief encourager, and 24/7 tech support, my kind, supportive husband Shawn Hall. I dedicate this dissertation to you for always believing in me and for staying awake on countless nights when you did not have to over the past 5 years to pray over me, motivate me, support me, dry my tears, and remind me to stay focused on my journey to attain a PhD in Public Health. I could not accomplish this without you and our two clever dogs, Fu and DaShi. You and the dogs kept me laughing to lift my spirits whenever I was exhausted and feeling down. All for one and one for all, forever!

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Chapter 1: Introduction to the Study

The use of invasive abdominal hysterectomies to treat uterine fibroids has a long history, and the procedure is still widely practiced, despite the emergence of more recent minimally invasive alternatives. In the early18th century, the treatment procedure of vaginal hysterectomy was often the only option for women with uterine fibroids, and 90% of those women died on the operating table (Amoah et al., 2022). In the 1930s, the invasive abdominal hysterectomy was the first documented type of hysterectomy procedure performed using anesthesia (Amoah et al., 2022). After the introduction of the invasive abdominal hysterectomy, there were very few advancements in treatment for fibroids until 1988, when Dr. Harry Reich conducted the first minimally invasive procedure, a laparoscopic hysterectomy (Chwalisz & Taylor, 2017). Currently in the United States approximately 90% of the 600,000 hysterectomies conducted yearly are for benign fibroids (American College of Obstetricians and Gynecologists [ACOG], 2021). Surprisingly, 60% of those hysterectomies are abdominal hysterectomies still performed through a large abdominal incision. Significant evidence supports that abdominal hysterectomies are associated with more complications such as pain, infections, and extended hospital stays than minimally invasive procedures (ACOG 2017; Pollack et al., 2020).

Black women are 3 to 4 times more likely than women of any other race to receive the most invasive treatment procedure of an abdominal hysterectomy instead of a less invasive and less damaging laparoscopic or robotic procedure (McClurg et al., 2020). Black women accounted for 55% of invasive abdominal hysterectomies for benign fibroids compared to 22% of White women (Alexander et al., 2019). The burden of fibroids also affects Latino, East Asian and other women of color, though at a much lower rate than Black women. Additionally, Latino, East Asian and other women of color have a higher rate of less invasive reproductive preserving treatment procedures and laparoscopic hysterectomies than Black women (Murji et al., 2020). Despite the many advances in reproductive health in the United States, the rate of abdominal hysterectomies has not significantly decreased for Black women.

In the United States, over a third of all hysterectomies are conducted on women between the childbearing age of 18 to 44. A review of Behavioral Risk Factor Surveillance System (BRFSS) data for 2006 to 2016 showed that the average age of hysterectomy for Black women was age 39 while the average age of hysterectomy for White women was age 47 (Gartner et al., 2020). Of growing concern is the increase in abdominal hysterectomies performed on Black women of childbearing age, thereby further affecting Black women’s maternal and reproductive health. There is not much research on less invasive treatments for benign fibroids in Black women because Black women needing surgery for fibroids are less likely to receive less invasive treatment procedures (Al-Hendy et al., 2017). I conducted this study to address a lack of knowledge on the factors contributing to the high percentage of abdominal hysterectomies performed on Black women in the United States. Such research was warranted because Black women continue to experience reproductive health disparities and higher morbidity and mortality rates than women of any other race. The study may contribute to positive social change through its exploration of the influences, choices, and decisions of Black women with fibroids who decided to have an abdominal hysterectomy. This knowledge could inform the development of education programs focused on educating Black women about less invasive treatment procedures (Aninye & Laitner, 2021)..

In this chapter, I state the problem, the purpose of the study, and research question. These sections will be followed by a discussion of the social ecological model (SEM) and the health belief model (HBM), both of which constituted the study's theoretical framework; I discuss how both models relate to the study approach and align with the research question. The discussion about the theoretical framework reveals the interconnectedness of the models and the lived experiences, influences, and choices that lead Black women to decide to have the most invasive treatment of abdominal hysterectomy for benign fibroids. An overview of the nature of the study follows, which includes details on the research design and methodology. Specific key terminology will be defined, and underlying assumptions critical to the study’s purpose will be briefly described. Specific aspects of the research study, such as its scope and delimitations and limitations, will be addressed, and, last, the study’s significance and potential contribution to social change will be discussed.

Background of the Study

Currently, researchers do not know why most Black women diagnosed with fibroids decide to undergo the most invasive treatment procedure of abdominal hysterectomy for benign fibroids. The disparity is so significant that in March 2020, the Uterine Fibroid Research and Education Act was introduced into Congress by now Vice President Kamala Harris. According to the Society of Women’s Health Research (2020), this Act will focus on what more can be done to address the complications from uterine fibroid treatment that lead to high maternal mortality and morbidity for Black women. The Act requires all women to receive the support, treatment options, and care they need, and supports public education for Black women on treatment procedures other than hysterectomy. The Act also focuses on research to identify the barriers Black women encounter that prevent them from accessing the latest trends in less invasive treatment of fibroids to ensure that they get equal support and information (Society for Women's Health Research, 2020). The Act is just one effort to address the fibroid treatment gap that disproportionately affects Black women's lives.

A study of medical records within a large U.S. health system showed that even when the same symptoms were present, different treatment options and access did not eliminate the disparity for Black women (Katon et al., 2019). Black women still received the most invasive treatment of abdominal hysterectomy at much higher rates than women of any other race within the same health system. In another significant study of prevalence trends and determinants of health in the United States using BRFSS data for 2006 to 2016, researchers found that, while the rate of abdominal hysterectomies decreased over time for other races, the rate remained steady for Black women, who accounted for 61% of all abdominal hysterectomies performed (Gartner et al., 2020). Several studies examining the clinical records of female veterans in the Veteran's Administration System found that Black women veterans were less likely to undergo minimally invasive hysterectomy treatment procedures than women veterans of other races (Callegari et al., 2019; Katon et al., 2019; Wang et al., 2021a). Black women are less likely to receive a minimally invasive hysterectomy and more likely to suffer complications after a hysterectomy (Alexander et al., 2019).

Overall, these findings suggest that additional exploration of Black female patients' perspectives is needed to better understand contributing factors to the disparity. The findings of a significant number of studies discussed in Chapter 2 support that a treatment disparity exists. However, researchers do not know why the disparity exists. Additionally, current minimally invasive fibroid treatment research is barely reflective and inclusive of the population most affected. In summary, this study may address a critical gap in the literature by providing insight on the population most affected by the fibroid treatment disparity. Further exploration of the lived experiences of Black women who decided to have the most invasive procedure of abdominal hysterectomy may provide a better understanding of what factors influenced their decision.

Problem Statement

The problem addressed in this qualitative study was that researchers do not know why most Black women diagnosed with fibroids decide to have the most invasive treatment procedure of abdominal hysterectomy for benign fibroids. Currently, in the United States, 80% of Black women are diagnosed with benign uterine fibroids by age 50 (McClurg et al., 2020). Patients who undergo a minimally invasive laparoscopic, robotic, or vaginal hysterectomy experience a lower rate of complications, blood transfusions, wound infections, bowel injury, and hernia of the incision (Callegari et al., 2019). Patients who experience an invasive abdominal hysterectomy have a higher mortality rate due to complications (Callegari et al., 2019). In the United States, Black women account for 55% of invasive abdominal hysterectomies for benign fibroids compared to 22% of White women (Yu et al., 2018). According to the ACOG (2021), gynecological best practices recommend using a minimally invasive treatment for benign fibroids.

The latest trend in fibroid treatment is laparoscopic hysterectomies. In 2020, research showed that in the United States, these procedures increased by 74%, and robot assisted hysterectomies increased by 24% for women of other races (Zaritsky et al., 2019). However, even with these improvements in fibroid treatment, as recently as 2020, the rate of Black women who receive abdominal hysterectomies for benign fibroids has still remained consistently high (McClurg et al., 2020). Black women are more likely to have an invasive abdominal hysterectomy instead of a less invasive, less damaging laparoscopic or robotic procedure (Sanei-Moghaddam et al., 2018). Evidence suggests that a racial disparity may exist in treating benign fibroids (Zaritsky et al., 2019). In this qualitative study, I addressed the problem by further exploring the lived experiences of Black women to understand the influences that led them to decide to have the most invasive treatment of abdominal hysterectomy for benign fibroids. Clearly, more research and awareness were needed to address this public health disparity.

Purpose of the Study

The purpose of this qualitative study was to explore the lived experiences of Black women who decided to have an invasive abdominal hysterectomy for benign fibroids. Although Black women are the population most affected by the treatment of hysterectomy for benign fibroids, their voices remain barely heard in the research (Zota & VanNoy, 2021). I sought to address this gap by exploring Black women's lived experience and insight on what influenced their treatment decision. This study may help to facilitate an understanding of the sensitive, personal choices and the factors that influenced their decision to undergo the most invasive treatment procedure for benign fibroids.

Research Question

The research question I sought to answer was, What are the lived experiences of Black women who decided to undergo the procedure of abdominal hysterectomy for benign fibroids?

Theoretical Framework

The main theoretical framework for this study was the SEM, as it has been widely used to explore the relationship between individuals and the levels of influence surrounding them. The SEM posits that multiple factors influence behavior through complex spheres of interactions among individuals and their environment (Salihu et al., 2015). The five levels of influence applied by the SEM are (a) microsystem, (b) mesosystem, (c) exosystem, (d) macrosystem, and (e) chronosystem (Bronfenbrenner, 1994). I applied the microsystem, macrosystem and chronosystem levels of influence in this study. The use of the SEM allowed me to take a deeper look into the worldview of each participant during the semistructured interviews to address the research question. Specifically, the microsystem, macrosystem and chronosystem spheres of the SEM were examined to better understand the participants' lived experiences and learn what influenced them to make a decision to have the most invasive procedure as treatment for benign fibroids.

I applied the HBM as a subtheory to uncover emerging themes related to the phenomenon and participants' lived experience of it (see Glanz et al., 2015). Application of the HBM allowed me to explore participants' lived experience between diagnosis and treatment to provide insight into what influenced their decision to have a hysterectomy for benign fibroids (see Rosenstock, 1990). The six constructs of the HBM are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Herrmann et al., 2018; Rosenstock, 1974). Only the perceived severity, perceived benefits, and cues to action constructs of the HBM were applied in this study. Linking these three constructs to semistructured interview questions, I answered the research question by exploring how each woman perceived the severity of their diagnosis and what perceived benefits influenced each participant's decision. I also explored what cues caused each woman to decide to undergo the recommended abdominal hysterectomy to better understand their lived experiences between the time of diagnosis and treatment. Exploring the lived experience between diagnosis and treatment was pivotal because several studies indicate that Black women tend to delay seeking treatment for fibroids (Scott, 2020).

I applied the cues to action construct of the HBM to explore what finally triggered each participant to make the sensitive personal decision to have an invasive abdominal hysterectomy for benign fibroids. The HBM was interconnected with the application of the SEM and linked to specific interview questions to explore the influences that led each woman to make the preference-sensitive decision. The major theoretical propositions will be explained in greater detail in Chapter 2.

In summary, the decision to have a hysterectomy means that a woman can no longer have children. Although Black women are the population disproportionately treated with invasive abdominal hysterectomies for benign fibroids, very few studies have considered the lived experiences of Black women and what led them to decide to have a hysterectomy (Cuthbertson et al., 2020). The application of the SEM and HBM to this research study provided rich contextual data on the lived experience of Black women and what influenced and triggered their decision to have an invasive abdominal hysterectomy.

Nature of the Study

In this generic qualitative study, I explored the lived experiences of Black women who chose to undergo the most invasive treatment procedure of abdominal hysterectomy for benign fibroids. I applied a hermeneutic phenomenological approach. Hermeneutic phenomenology, which Heidegger originally theorized, is a tool for focusing on the lived experience of the study population (Heidegger, 1962). The purpose of a phenomenological approach in research is to clarify and inform how individuals understand certain phenomena (Patton, 2015). A hermeneutic phenomenology approach posits that individuals have the power of choice; however, their choices are affected by certain conditions and influenced by their daily reality (Heidegger, 1962). Understanding participants' lived experience can yield in-depth understanding of a research phenomenon, Ravitch and Carl (2016) noted. In this study, I wanted to explore Black women’s lived experiences regarding their choices, influences, and decisions to better understand what led them to undergo the most invasive procedure for benign fibroids.

For this study, I recruited and conducted semistructured interviews with Black women, age 18 and older, who had experienced the phenomenon of abdominal hysterectomy for benign fibroids within the past 16 years. The period of 16 years was selected for this study because more minimally invasive procedures such as laparoscopic and robot-assisted hysterectomies became mainstream and covered by insurance in 2006 (Aarts et al., 2015). The semistructured interviews were conducted and recorded via Zoom videoconferencing. Interpretative phenomenological analysis (IPA) was used to explore and make sense of each participant's lived experience and the influences and choices that led to their decision to undergo an invasive hysterectomy for benign fibroids (see Heidegger, 1962). Through this interpretative approach, I analyzed and contextualized the data to summarize and establish the emerging interconnectedness within the data (see Patton, 2015). I gathered data through semistructured interviews, wherein participants shared their lived experiences including their thoughts, choices, influences, and decisions; this allowed me to obtain a complete picture of each participant's experience with the phenomenon (see Crawford & Lynn, 2016).

I audio- and video-recorded each interview on Zoom with each participant's consent. A backup sound recorder application with a sensitive external microphone was used to record each interview to ensure that the interview was captured. I demonstrated that the research findings were the lived experience of the participants by preserving audit trails with field notes, journaling of coding methodology, and emerging themes. The interviews were transcribed using the real-time transcription feature in Zoom and analyzed using NVivo 12 Qualitative Data Analysis software, (NVivo 12 QDA) (see

Rubin & Rubin, 2012). Participants were allowed to review and make changes to the transcript to clarify what was said before the research was finalized and published. No identifying data were present in the stored file, and the data are protected and stored electronically (see Rubin & Rubin, 2012). I identified and analyzed themes to compare the data emerging as an understanding of the lived experience was gained (see Heidegger, 1962). I organized the data by emerging themes and manually coded and condensed the data. Through this inductive approach, I analyzed and contextualized the data to summarize and establish the emerging interconnectedness within the data (see Patton, 2015).

Definitions

Some terms used in the study have interchangeable meanings that may depend on applicability. Following are the definitions for some of these critical terms:

Abdominal hysterectomy: One of the most expensive, invasive fibroid treatment procedures requiring a large incision across the abdomen. The abdominal hysterectomy has the highest rate of long-term complications of all fibroid treatments (ACOG, 2021).

Black: Participants who self-identify as Black or African American.

Fibroids: Smooth noncancerous neoplasms that grow from organs in the body but are typically found in the uterus (Fortin et al., 2021). Other terms for fibroids used interchangeably in scientific discourse are *uterine fibroids* or *leiomyomas*.

Hysterectomy: An invasive surgical procedure that completely removes the uterus from a woman’s body (ACOG, 2017). A hysterectomy can occur by a vaginal, partial, total, or radical procedure (ACOG, 2021).

Partial hysterectomy: A surgical procedure also referred to as a *subtotal* or *supracervical hysterectomy* that involves keeping the cervix but removing the upper portion of the uterus (Schwab, 2001).

Total hysterectomy: A surgical procedure that involves the removal of the cervix and uterus through an abdominal incision (Schwab, 2001). A total hysterectomy may also include removal of the ovaries and fallopian tubes (Schwab, 2001).

Radical hysterectomy: A surgical procedure that is performed when cancer is present and is not typically performed for benign fibroids. A radical hysterectomy procedure involves removing the cervix, uterus, connecting tissue, one or both ovaries, and the top of the vagina, which may include the ovaries and fallopian tubes (Schwab, 2001).

Vaginal hysterectomy: A surgical procedures that requires early detection of fibroids. It is a surgical procedure that involves the surgical removal of the uterus through the vagina (Schwab, 2001).

Assumptions

I had several assumptions in conducting this study. As discussed, a hysterectomy ends a woman’s ability to have children and is a personal, sensitive decision that can become emotionally distressing and uncomfortable to discuss. One assumption for this qualitative phenomenological study was that Black women who had an abdominal hysterectomy for benign fibroids would be willing and open to sharing their lived experiences. For this study, I conducted semistructured interviews and assumed that the participants could subjectively describe their life experiences. Additionally, I assumed that all Black women participating in this study were not well informed about less invasive treatment options for benign fibroids and thought an abdominal hysterectomy was the best or only option. It was also assumed that if the women had been educated about their options, they may have chosen to have a minimally invasive procedure for treating benign fibroids. Last, I assumed that conducting semistructured interviews and asking follow-up questions would allow common themes to emerge in participant responses.

Scope and Delimitations

My intent for this study was to address the gap in the literature on the lived experiences of Black women of abdominal hysterectomy; this population disproportionately undergoes this procedure, which is the most invasive treatment for benign fibroids (Baird et al., 2020). Gaining a better understanding of the treatment choices Black women are given and the factors that influenced their decision to have the most invasive treatment procedure may help better explain the current disparity so that awareness, education, and interventions can be more effectively tailored (see Vodovotz et al., 2020). The target population for this study was Black women aged 18 or older who had an abdominal hysterectomy for benign fibroids in the past 16 years. I chose participants based on their ability to provide rich and meaningful data about their lived experiences through semistructured interviews and follow-up questions. The participants needed to be fluent in understanding and speaking the English language. In addition to the semistructured interviews and follow-up questions, I used a prescreening form to ensure that participants identified their race as Black or African American. I have a personal interest in the topic of this study based on my lived experience as a Black woman with no children who had a hysterectomy at a young age for benign fibroids 20 years ago.

Limitations

My intent was to provide meaningful, rich data about the phenomenon of investigation as it relates to Black women. Generalizability of this study is limited. I am aware that the small sample size and sample selection may be a limitation of the study as the lived experiences shared may not represent all Black women who have experienced the phenomenon. The transferability of findings is also limited by sex and race; the findings are limited to Black women. I determined that this was a meaningful delimitation because Black women are the population most disproportionately treated with abdominal hysterectomy for benign fibroids (Lawson, 2017). Potential barriers to the study included possible challenges with recruiting women for the study. Talking about the hysterectomy and what influenced their decision may have been emotionally challenging for some women and could have influenced their decision not to complete the interview (see Bloomberg & Volpe, 2018). Additionally, as a Black woman who had an abdominal hysterectomy for benign fibroids over 20 years ago, I remained aware of potential researcher-induced biases that might have influenced the study (see Creswell & Creswell, 2017). My experience with the phenomenon can have presented researcher bias.

However, I bracketed my experiences and engaged in journaling, in addition to having participants validate my interpretation of the data, to account for researcher bias

(Ravitch & Carl, 2016). I did not share my personal history with the phenomenon to prevent unintentional influence on answers to the research question. I used several strategies to limit issues of dependability. I used Zoom's record and transcription features to record participant responses and transcribe them verbatim. Participant validation of interview transcripts was used to reinforce the credibility and trustworthiness of the data and reassure the absence of researcher bias.

Significance

A well-known disparity exists in the reproductive health of Black women in the United States. Treatment rates for abdominal hysterectomies performed on Black women of childbearing age have remained high for well over 2 decades, thereby further affecting Black women’s reproductive and maternal health and fertility rates (Aninye & Laitner, 2021). Research studies have shown that Black women are more likely to be treated with an invasive abdominal hysterectomy than women of any other race (McClurg et al., 2020). However, researchers still do not know why this disparity exists. Women who have an invasive abdominal hysterectomy suffer more complications and have a higher mortality and morbidity rate than those who receive minimally invasive treatment for benign fibroids (Bonafede et al., 2018). Adding to this issue is the long history of mistrust between the U.S. government, the medical community, and the Black community. Currently, Black women comprise less than 15% of participants in fibroid treatment clinical trials in the United States, and very little government research funding is targeted towards addressing this women’s health disparity (Alexander et al., 2019). Therefore, a gap exists in the research. The lived experiences of the population affected by the most invasive treatment for benign fibroids are missing from the research. This study may add to the literature by ensuring that the voice of the population most affected but often excluded in clinical research is included in current fibroid research (see McClurg et al., 2020). Exploring the influences, choices, and decisions of Black women with fibroids who decide to have an abdominal hysterectomy may have positive social change implications for it may inform the development of education programs focused on educating Black women about treatment procedures that are less invasive than an abdominal hysterectomy.

Summary

Abdominal hysterectomy is the most invasive procedure for the treatment of benign fibroids. Despite the many advances in reproductive health in the United States, the reproductive health of Black women, including the number of abdominal hysterectomies, has not decreased. Black women are three to four times more likely to have an abdominal hysterectomy for benign fibroids than women of any other race. Few researchers have explored why Black women decide to have the most invasive treatment procedure for benign fibroids. In Chapter 2, I provide an exhaustive discussion of the literature on the study topic. Chapter 2 also includes a detailed explanation of how the SEM and the HBM were applied to address the gap in the literature. I used both models to explore the lived experiences of Black women to learn what influenced their decision to have the most invasive treatment procedure of abdominal hysterectomy for benign fibroids.

Chapter 2: Literature Review

Introduction

Extensive research findings support that by age 50, 80% of Black women in the United States are diagnosed with benign uterine fibroids (McClurg et al., 2020). Though research has shown that there is no one best way to treat benign fibroids, gynecological best practices recommend minimally invasive treatment procedures (Pollack et al., 2020). Less minimally invasive procedures such as laparoscopic and robot-assisted hysterectomies became mainstream in the United States after they were covered by insurance in 2006 (Aarts et al., 2015). According to researchers, 1 in 5 Black women are unaware of treatment options other than a hysterectomy for benign fibroids (ACOG, 2021). Black women are also 4 times more likely than women of any other race to receive a treatment plan for an invasive abdominal hysterectomy instead of a less invasive and less damaging laparoscopic or robotic procedure (McClurg et al., 2020). Therefore, even with the advancements in fibroid treatment, the rate of Black women receiving an abdominal hysterectomy for benign fibroids remains consistently high (McClurg et al., 2020). In this chapter, I will review the literature on Black women and benign fibroids, treatment for benign fibroids, the underrepresentation of Black women in fibroid research, and the theoretical framework selected for this study.

Literature Search Strategy

I used the following databases and search engines to find literature review sources: Thoreau (a Walden University multidatabase search tool), ERIC, Med Line with Full Text, PubMed, Google Scholar, and Dissertations & Theses at Walden University. I conducted an electronic search of the Walden University library using the following key search terms: *fibroids, benign fibroids, intramural fibroids, leiomyoma, leiomyoma diagnosis*, *leiomyoma treatment*, *myoma*, *uterine neoplasms, minimally invasive and fibroids, African American, Black and leiomyoma*, *racial health disparity and fibroids*, *reproductive health disparity*, *minimally invasive hysterectomy*, *fibroid treatment cost comparison*, *hysterectomy surgical intervention*, *fibroid treatment patterns*, *social ecological model, the health belief model, phenomenology,* and *underserved women in gynecology*. The journal articles used in this literature review are peer-reviewed qualitative, quantitative, and mixed methods studies presented in English and published between 1997 and 2020. Analysis of the search results revealed that Black women were often underrepresented in data sets and published studies. A thorough review of the literature revealed that many peer-reviewed research studies were over 7 years old. The lack of recent peer-reviewed research could significantly impact the researchers' understanding of the lived experience and have further implications about the lack of data to impact policy and health disparities for Black women meaningfully.

Identification of the Literature Gap

Black women are significantly less likely to be aware of less invasive treatment options for benign fibroids (Keller et al., 2022). Racial disparities in fibroid treatment are also evident (Bonine et al., 2020), with Black women having a 50% higher mortality rate than White women who have undergone a hysterectomy (Baird et al., 2020). Researchers do not know why Black women are more likely to undergo the invasive treatment of abdominal hysterectomy for benign fibroids (Price et al., 2017; Sengoba et al., 2017).

Most fibroid studies exclude race, although Black women are the population most often diagnosed with fibroids (Sanei-Moghaddam et al., 2018). The voices of Black women and their lived experiences regarding their decision to have an invasive treatment of abdominal hysterectomy for benign fibroids have not been present in the research (Lawson, 2017).

More research is needed to understand why most Black women still have an invasive abdominal hysterectomy for benign fibroids despite the advances in minimally invasive fibroid treatment. These findings suggest there is an unmet need for education about minimally invasive, low-risk treatments for benign fibroids in the medical and Black community (Riggan et al., 2021). My research may add to the current body of research by providing insight on the lived experiences of the population that is disproportionately affected yet scantily present in the research. I explored what factors influence Black women to decide to have a hysterectomy as treatment for benign fibroids.

Theoretical Framework

The main component of the theoretical framework was the SEM. I applied the microsystem, macrosystem, and chronosystem levels of the SEM in this phenomenological study to explore each participant’s worldview and lived experiences that influenced them in distinct and powerful ways (see Cuthbertson et al., 2020). The HBM was applied as a subtheory to uncover emerging themes related to the phenomenon and the lived experience (see Glanz et al., 2015). I applied the HBM to further explore the participants’ perceptions to provide insight into what influenced their decision to have a hysterectomy for benign fibroids (see Herrmann et al., 2018). Through interconnectedness, the SEM and the HBM were applied to explore the research question of how the participants perceived their lived experiences with deciding to have an abdominal hysterectomy for benign fibroids (see Herrmann et al., 2018). I used the logical connections between the frameworks and the nature of my study to explore how an individual and the surrounding environment can shape the decision-making process, perceptions, and lived experience (see Doll et al., 2019).

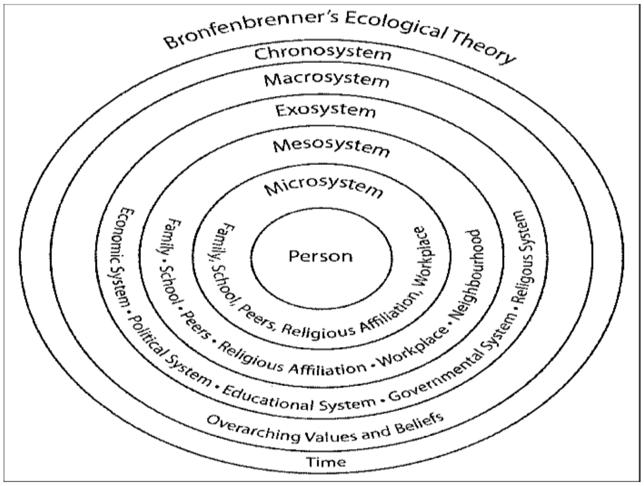
Many sources in my research describe having a hysterectomy for benign fibroids as a sensitive personal decision with risks and benefits. Many researchers, such as Berman et al. (2022), have acknowledged the disparity in the use of hysterectomy as a predominant treatment for benign fibroids in Black women. The lived experiences of the Black participants in my research offer an opportunity to better understand and show the link between the women, their environment, and the decision-making process that led to their choice to undergo an invasive hysterectomy as treatment for benign fibroids (see Glanz et al., 2015; Heidegger, 1962). I explored and identified the common themes that may be further linked to causal factors for the disparity. In doing so, I added to the scant body of research about Black women diagnosed with benign fibroids.

Social Ecological Model

Researchers in various disciplines such as education, public health, psychology, sociology, and biology have applied ecologial models (Kilanowski, 2017). For many decades, these models have been well regarded in social science research. Renowned psychologist Kurt Lewin first applied an ecological model called field theory, which states that patterns exist between the individual and their environment. Lewin believed that the environment influences behavior (Cramer & Kapusta, 2017). Research by psychologist Roger Barker supported that settings are connected to individuals' actions and spheres of influence (Cramer & Kapusta, 2017). In 1979, child psychologist Urie Bronfenbrenner developed a SEM focused on the influences that relationships and the environment have on an individual’s behavior and decision-making (Kilanowski, 2017). The spectrum of ecological models is better understood across disciplines (Bogardus et al., 2019), and researchers continuously utilize the SEM to deepen their understanding of the experiences that influence human development. Figure 1 is an illustration of Bronfenbrenner's SEM.

Figure 1

Bronfenbrenner's Social Ecological Model



Note. From "Moving 'Eco' Back Into Social Ecological Models: A Proposal to Reorient Ecological Literacy Into Human Developmental Models and School Systems," by N. R. G. Stanger, 2011, *Human Ecology Review, 18*(2), p. 169 (https://www.jstor.org/stable/24707472). Copyright 2011 by Society for Human Ecology.

The application of the SEM assumes that multiple factors influence behavior through complex spheres of interactions among individuals and the environment (Cramer & Kapusta, 2017). The SEM applies five levels of influence in public health through multiple spheres surrounding the individual. There is a complex interaction between the individual, interpersonal, organizational, community, and political spheres.

SEM Levels of Influence

Microsystem. The microsystem is a sphere comprised of the immediate day-to-day environment including age, family, peers, religious affiliations, and the workplace (Bronfenbrenner, 1994). It is defined by the constructs observed and how the individual perceives their role in each setting, and the value they assign to it in their life. This value system often plays an intricate role in behavior and decision-making (Bronfenbrenner, 1994).

Mesosystem. The mesosystem incorporates interrelated settings, often with robust time demands that contribute to neglect in other settings. The mesosystems may be linked through various social and cultural networks and have norms and support systems. Interaction with social networks in a mesosystem can expand an individual's worldview and influence interpersonal. However, as an individual gains maturity, these influences may become less influential (Bronfenbrenner, 1994).

Exosystem. Another sphere or level within the SEM's circle is the exosystem, which comprises the political, government, and economic systems. The individual does not have control of the exosystem but is directly affected by it. The exosystem is so powerful that it can significantly impact the individual's life (Bronfenbrenner, 1994).

Macrosystem. The fourth sphere is a macrosystem where norms, culture, overarching values and beliefs affect the microsystem level. Aspects of the macrosystem such as socioeconomic status and race can be formidable barriers that influence each level (Bronfenbrenner, 1994).

Chronosystem. The fifth sphere of the SEM, the chronosystem, encompasses major life developments and transitions as they occur over time. An individual's choices and actions, and the environment in which they occur, are linked on all levels of the model, as depicted in Figure 1.

The microsystem, macrosystem and chronosystem spheres of the SEM will be applied to understand Black women's choices and influences that resulted in their decision to undergo an invasive abdominal hysterectomy for benign fibroids (see Cramer & Kapusta, 2017). Exploration of these three levels of the SEM may further inform why disparities in treating benign fibroids exist for Black women.

Health Belief Model

Introduced in the 1950s, the HBM explains an individual's health decisions (Rosenstock, 1974). The constructs of HBM are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action (Carpenter, 2010). Over the years, researchers have used the perceived benefits construct of the HBM to better understand why an individual would decide to accept or not accept a recommended health diagnosis or treatment (Herrmann et al., 2018). Deciding to undergo a hysterectomy for benign fibroids is a preference-sensitive decision. I used the HBM as a subtheory to explore the lived experiences involved in the decision-making process leading up to the decision to have a hysterectomy for benign fibroids (see Herrmann et al., 2018). The HBM is a cognitive-based model; therefore, the HBM is not used to examine emotional components of behavioral health change. The HBM includes the following six key constructs: (a) perceived susceptibility, (b) perceived severity, (c) perceived benefits, (d) perceived barriers, (e) cues to action, and (f) self-efficacy (Carpenter, 2010).

Perceived Susceptibility

According to Rosenstock (1974), perceived susceptibility is the belief that an individual is vulnerable to or at risk of becoming ill. Perceived susceptibility includes accepting the symptoms and diagnosis and believing that the condition may reoccur. The degree of risk and acceptance is based on everyone’s knowledge and experiences. If the individual believes that they are susceptible, there is a greater chance that they will act (Glanz et al., 2015).

Perceived Severity

Perceived severity postulates the belief that a condition is severe enough to be considered a threat. The perceived severity may impact the individual’s ability to face the situation and make decisions because of fear and anxiety. If individuals have low perceived severity, they may delay making essential health decisions (Rosenstock, 1974).

Perceived Benefit

The perceived benefits measure the belief that the prescribed course of action may minimize the risk of the condition. Individuals determine their perceived benefit based on their understanding of the condition and course of action. The course of action taken will also be based on the perceived susceptibility and perceived severity (Rosenstock, 1974).

Perceived Barriers

The perceived barriers are the perceived obstacles that hinder the individual from carrying out the recommended actions to improve their health. The individual weighs the perceived barriers against what they perceive to be the cost, tangible or psychological (Glanz et al., 2015; Rosenstock, 1974).

Cues to Action

Cues to action are the stimuli that will trigger action for each individual. The cues to action may differ for everyone. Cues may be internal such as symptoms or an illness, or external such as advice from family members, but once weighed, the cues get each individual prepared to take action (Rosenstock, 1974).

Self-Efficacy

The last construct of the HBM, self-efficacy, describes the perceived belief in the individual’s capabilities to manage and execute the prescribed course of action. Self-efficacy is determined by how individuals motivate themselves and their belief in the strength of their self-efficacy (Rosenstock, 1974).

The HBM considers individuals’ beliefs about exposure and associated risks of illness, their perceptions about taking preventive action, and the perceived barriers that influence their level of readiness to take preventive action (Doll et al., 2019). Behavioral change limitations in the effectiveness of the HBM result from perceived susceptibility and the practice of using fear-based communication in public health programs (Glanz et al., 2015). Research shows that fear-based interventions yield insignificant long-term behavioral change. The HBM is a descriptive theory rather than an explanatory theory since the HBM does not provide a strategy for behavioral change (Doll et al., 2019; Glanz et al., 2015). The perceived susceptibility predicts the one-time intention of behavioral change and cannot sustain motivation for long-term change (Creswell, 2009).

Additionally, the HBM does not consider the environment or other factors that may prevent the women from following the recommended treatment plan (Creswell, 2009). This limitation is significant as it may be a barrier for Black women and other minority populations due to cultural differences and the public health threat of structural racism (Al-Hendy et al., 2017). The intent of this study was not behavioral change. I used the application of the HBM as a subtheory to explore the women’s perceived severity, perceived benefits, and cues to action to learn what led each woman decide to have a hysterectomy for benign fibroids (see Glanz et al., 2015; Herrmann et al., 2018).

Application of the Social Ecological Model and Health Belief Model

Through interconnectedness, the SEM and the HBM were applied to explore the research question on how the women perceived their lived experiences with deciding to undergo an abdominal hysterectomy for benign fibroids (see Akpenpuun et al., 2019; Herrmann et al., 2018). The models enhanced this phenomenological study by exploring the decisions made during the period after diagnosis and leading up to treatment for benign fibroids. It is important to include the exploration of the lived experience for the period between diagnosis and treatment because research shows that 65% of Black women wait longer than average to seek treatment. The SEM and HBM were used to further explore and inform on the beliefs of the women and what influenced them during that period and what triggered them to make a decision to undergo an abdominal hysterectomy for benign fibroids (see Chwalisz & Taylor, 2017). The microsystem layer of the SEM enables the researcher to explore the day-to-day life of each women including how new developments and their network influenced their decisions (Bogardus et al., 2019). Exploring the macrosystem layer of the SEM revealed the women's beliefs and perceptions about the phenomenon and how it shaped their decisions. The chronosystem layer of the SEM enables a researcher to examine how personal, social, structural, and other factors can influence individuals and their worldview (Cuthbertson et al., 2020). Exploration of the microsystem, macrosystem and chronosystem revealed the role and direct influence the linkages the SEM play in each participant's decision to have the most invasive abdominal hysterectomy procedure as treatment for benign fibroids (see Herrmann et al., 2018; Kilanowski, 2017). Three components of the HBM, perceived severity, perceived benefits, and cues to action, were used to explore and understand what led each woman decide to have a hysterectomy for benign fibroids. Application of these three constructs of the HBM provided insight on the decision-making behavior that ultimately led the women to make the decision to have an invasive abdominal hysterectomy for benign fibroids.

Through interconnectedness, the SEM and the HBM were applied to uncover emerging themes and explore the research question on how the women perceived their decision to have an abdominal hysterectomy for benign fibroids (see Cramer & Kapusta, 2017; Lawson, 2017). It is vital to explore Black women's influences and decision-making behavior because Black women represent 55% of invasive abdominal hysterectomies for benign fibroids compared to 22% of White women (Zaritsky et al., 2019). Exploration of the influences on treatment decisions made by Black women with benign fibroids provide context that is currently rarely found in the research (Riggan et al., 2021). Understanding what influences their decisions and causes them to act by making a decision to have the most invasive procedure as treatment for benign may reveal implications for more targeted fibroid treatment awareness and education programs specifically designed and focused on Black women.

Literature Review Related to Key Variables and/or Concepts

The articles in this literature review were chosen to increase awareness about Black women diagnosed and treated with hysterectomy for benign fibroids (see Zaritsky et al., 2019). Some of the articles presented are about women in general and fibroids or reproductive health. Consistently high hysterectomy rates for benign fibroids among Black women is a public health problem that suggests a racial disparity in fibroid treatment. In a predictive study of the Nationwide Inpatient Sample of Healthcare Cost and Utilization Project, researchers calculated the number of hospitalizations for fibroid-related hysterectomies for women aged 15 to 54 (Wechter et al., 2011). The researchers found that Black women would be significantly impacted with an increase of 31% in fibroid-related hysterectomies by the year 2050 (Wechter et al., 2011). I explored the lived experience of experiences of Black women with hysterectomy for benign fibroids to add to the research and gain a better understanding of their lived experiences. My study is significant because while Black women disproportionately receive the treatment procedure of an invasive abdominal hysterectomy for benign fibroids, most fibroid studies exclude race (Lawson, 2017). Black women are often missing from clinical fibroid research. Only a few older phenomenological studies about fibroids and Black women were found in an exhaustive search of the literature (Marsh et al., 2018). Therefore, while Black women are the population disparately affected by the treatment of hysterectomy for benign fibroids, the voices of Black women sharing their lived experience and insight on what influenced their treatment decision is barely present in the research (Lawson, 2017). My dissertation research contributes to the field of public health by informing why and how Black women often make the sensitive decision to have a hysterectomy for benign fibroids instead of accessing the latest minimally invasive procedures for the treatment of benign fibroids.

Description and Prevalence of Benign Fibroids

Benign fibroids are noncancerous neoplasms located in the interior or exterior of the uterus (ACOG, 2021). The medical term leiomyoma or myoma also refers to fibroids (ACOG, 2021). A fibroid diagnosis may consist of one fibroid, or many fibroids may be present (Chen et al., 2018). Fibroids may change in size over time. Each fibroid may be different in size ranging from the size of a grape to a melon.

Benign fibroids are often noncancerous and not life-threatening but cause painful, severe complications if not treated (Pollack et al., 2020). Fibroids are determined to be benign through pathology (Chen et al., 2018). Symptoms include fertility issues, heavy bleeding, anemia, chronic fatigue, painful intercourse, back pain, severe cramping and bloating, and an enlarged abdomen (Fuldeore & Soliman, 2017).

Fibroids can be detected during a routine pelvic exam or through ultrasonography (Fuldeore & Soliman, 2017). Other advanced imaging studies may be required, such as magnetic resonance imaging, hysterosonography, hysterosalpingography, or hysteroscopy (Fuldeore & Soliman, 2017). However, diagnosis is frequently prolonged because the symptoms mimic many other gynecological conditions like endometriosis (Ali et al., 2018). Severe pain and other symptoms hinder women from exercising, socializing, and performing routine daily tasks (Wise & Laughlin-Tommaso, 2016). Although not cancerous, fibroids significantly affect the quality of life for millions of women every day.

In the United States, over 7 million women suffer from the symptoms of uterine fibroids each year (Bonine et al., 2020). It is highly likely that most women will develop fibroids. Due to varying methods used for diagnosis, a wide variance exists in the incidence of fibroids (217–3745 cases per 100, 000 women-years) and the prevalence rate (4.5–68.6%) for women in the United States (Stewart et al., 2017). Researchers estimated that over a quarter of Black women ages 18 to 30 develop fibroids in comparison to about 6% of White women (Zota & VanNoy, 2021). By age 35, over 60% of Black women are diagnosed with benign fibroids compared to approximately 40% of White women (Aninye & Laitner, 2021). By age 50, more than 85% of Black women are diagnosed with fibroids compared to 50% of White women (McClurg et al., 2020). A cross-sectional study of over 300,000 women in the United States showed that Black women developed fibroids much earlier than women of other races (Yu et al., 2018). Findings showed that the risk of developing fibroids at a much earlier age was 4 times greater in Black women by age 35.

While the prevalence of fibroids in the United States is underestimated due to asymptomatic women, research shows that Black women historically suffer higher fibroids, fibroid-related anemia, pelvic pain, and fertility complications than any other racial or ethnic group (Baird et al., 2020). Historically, there have been many unclear long-standing theories about why Black women receive hysterectomies for benign fibroids at much higher rates than women of any other race. I explored what influences Black women to have a hysterectomy for benign fibroids.

Contributing Factors to Fibroid Development in Black Women

Very little is known about factors that disproportionately impact the reproductive health and fertility of Black women diagnosed with fibroids (Danilyants et al., 2020). The findings of numerous research studies show that Black women develop fibroids earlier in life (Giuliani et al., 2020). Research study findings also indicate that Black women tend to experience more numerous and larger fibroids, which cause more severe symptoms and negatively impact their quality of life (Giuliani et al., 2020; Gray et al., 2020). According to the U.S. Department of Health and Human Services, Office on Women’s Health, some of the key factors that can increase the risk of developing fibroids are age, race, and obesity (Sanei-Moghaddam et al., 2018).

Age

In a study of medical records by the National Institute of Environmental Health Sciences, fibroid screening data from White and Black women aged 35 to 49 years old were randomly selected and analyzed (Giuliani et al., 2020). Findings showed that while White and Black women developed fibroids before menopause, the age-specific incidence of fibroids in the early 20s was significantly higher for Black women. McClurg et al.'s (2020) findings also showed that the cumulative incidence of fibroids before age 50 was significantly higher in Black women (85%) than in White women (60%). The study revealed significant age-related differences between White and Black women diagnosed with fibroids. According to researchers, by age 35, 60% of Black women had already developed a greater number of fibroids that were larger in size than White women of the same age. Underrepresentation of Black women in fibroid clinical trials has limited the research on this contributing factor. Researchers cannot explain the differences in the size and number of fibroids present in Black women at such an early age.

Race

Race has also been examined and believed to be a contributing factor to which women will develop fibroids. In fact, African ancestry is the most significant key risk factor for the development of fibroids. Black women are at the highest risk, being twice more likely to have fibroids than other women of color and 4 times more likely than White women (Aninye & Laitner, 2021). A systematic review of uterine fibroid studies across the United States and findings from the Nurses Health Study II showed that race was the only risk factor repeatedly significantly linked to increased incidence of fibroids in Black women (Al-Hendy et al., 2017). Researchers are not clear why Black women have a higher prevalence and burden of the disease. Some researchers have posited that lifelong systemic racism and health care disparities play a role in the increased risk for

Black women (Al-Hendy et al., 2017; Aninye & Laitner, 2021). While this may explain the higher incidence of fibroids in Black women, studies have found that these differences do not fully support or explain why Black women have a higher rate of invasive abdominal hysterectomies (Al-Hendy et al., 2017; Aninye & Laitner, 2021). Additionally, most research on age as a risk factor originates from a cohort of three pivotal studies conducted in the last decade (Leyland et al., 2022). Most other fibroid studies do not include multi-ethnic populations; therefore, limited understanding exists about race as a contributing factor to the disparity.

Obesity

Research suggests that there is a relationship between high body fat and the development of fibroids. Studies have shown that obesity among other risk factors such as race, family history, and lifestyle can play a role in the development of fibroids. A systematic review of uterine fibroid studies across the United States and findings from the Nurses' Health Study II (NHSII) suggest that obesity and the consumption of a high-fat diet are contributing factors that put Black at higher risk for fibroids (Al-Hendy et al., 2017). Research has shown that Black women have higher rates of obesity associated with chronic diseases such as high blood pressure and diabetes and that may play a role in making Black women more susceptible to fibroids (Al-Hendy et al., 2017). Findings from a national study conducted by the ACOG revealed that most Black women diagnosed with fibroids had a much higher body mass index than White women in the study (ACOG, 2017). A literature review of race and hysterectomy rates was conducted by Yu et al. (2018). The study findings suggest that obesity and genetic differences in estrogen metabolism, result in a higher body mass index and body weight at a younger age and a higher prevalence of fibroids in Black women (Yu et al., 2018). The lack of strong empirical evidence significantly linking obesity and other specific risk factors to the most affected disparate population indicates the need for more research that includes the voices of the population most affected to understand the phenomenon better.

Additionally, beliefs about the origin of the treatment disparities further complicate the scant presence of Black women in fibroid research. Scott (2020) argued that hysterectomies have historically been used to sterilize Black women. As discussed in Scott (2020), from 1929 to 1974, North Carolina implemented a eugenics program involuntarily sterilizing over 7,600 Black men through vasectomy and castration and Black women through hysterectomy to decrease the Black population who were seen as genetically inferior. According to Scott, mistrust of the health care system may lead Black women to delay talking to their doctors about symptoms and further delaying decisions about treatment. Black women’s delay in treatment may adversely impact the types of treatment procedures feasible based on the severity of their symptoms and the size of their fibroids (Scott, 2020). Therefore, it is important that the voices of the population most affected by phenomenon be present in the research.

Costs of Symptoms

Black women with fibroids are more likely to visit the emergency room with prolonged, excessive bleeding, severe anemia, low blood cell count, chronic fatigue, and back and abdominal pain than women of any other race (Pollack et al., 2020). Research findings suggest that the prevalence of fibroids in the population is underestimated because many women were asymptomatic women for many years and did not know they had fibroids (Yu et al., 2018). Findings of a population-based study about the burden, prevalence, and treatment of uterine fibroids, suggest that, on average, diagnosis time is often prolonged by overlapping symptoms that mirror endometriosis, adenomyosis, and other gynecologic conditions (Al-Hendy et al., 2021). The study also revealed that of the 18,330 women surveyed, 71% of Black women sought over-the-counter symptom relief medications and did not discuss their symptoms with a doctor before diagnosis (Al-Hendy et al., 2021). In contrast, 60% of White women talked to at least two or three doctors about their symptoms before diagnosis (Fortin et al., 2021).

Approximately 75% of the Black women reported that while their symptoms frequently significantly impacted their quality of life in social and employment settings, they did not speak to their doctors about their symptoms (Fortin et al., 2021). In a population survey, 80% of Black women reported painful sex, heavy menses, anemia, frequent urination, and other symptoms as normal (Borah et al., 2017). In another cross-sectional community survey completed by a convenience. Black women reported that their symptoms negatively affected the quality of their life and work productivity (Borah et al., 2017). Black women with fibroids report more days missed at work, less social life, challenges with self-image and relationships, and suffered challenges with social and emotional well-being (Zota & VanNoy, 2021). According to the American Academy of Family Physicians, only about 12% of Black women reported symptoms or sought medical treatment for their symptoms from their doctor (Schlaff et al., 2020). A retrospective cohort study to estimate the trend and prevalence of fibroids in the United

States showed that, on average, White women sought treatment an average of 1.5 years after first experiencing adverse symptoms (Schlaff et al., 2020). The study revealed that Black women sought treatment an average of 4.8 years after experiencing symptoms. Black women have higher hospitalization rates and are up to 3 to 4 times more likely to undergo an invasive abdominal hysterectomy for benign fibroids than White women (Soliman et al., 2017). Further complicating the racial and health disparity of fibroids disproportionately affecting Black women is that most Black women are not diagnosed early (Hartmann et al., 2017). These studies show a lack of awareness among Black women about the possible adverse health impact of not seeking early intervention by reporting their life-altering symptoms to their doctor, thereby possibly delaying treatment that could limit their treatment options, overall health, and reproductive health outcomes.

Although the economic burden of fibroid symptoms in Black women is undocumented, research shows that the overall economic burden of fibroid symptoms in the United States is $6–35 billion annually, including indirect costs for lost time and work (Aninye & Laitner, 2021). Black women bear greater economic burden than White women because they have the highest incidence of fibroids and are the population most treated with hysterectomy for benign fibroids (Aninye & Laitner, 2021). Black women have more uterine fibroid surgeries, although historically, Black women have had less access to adequate medical care (Bonine et al., 2020). Bonafede et al. (2018) estimated the differences in the cost of common uterine fibroid treatments of hysterectomy, myomectomy, endometrial ablation, or uterine artery embolization (UAE). Researchers used claims data from 2011 to 2016 to identify a population of women over the age of 30 with continuous insurance coverage for 12 months before and 12 months after being diagnosed with fibroids (Bonafede et al., 2018). Findings of the study showed that women who were treated by myomectomy, endometrial ablation, or UAE had a history of more doctor visits than the women who received a hysterectomy as treatment (Bonafede et al., 2018).

Study findings revealed that 80% of the women who had hysterectomies were Black, and the treatment cost for an abdominal hysterectomy was approximately $25,000 compared to an average cost of $7,000–$17,000 for the treatment by myomectomy, endometrial ablation, or UAE (Wang et al., 2022). In another retrospective matched cohort study, an IBM MarketScan Commercial Claims and Encounters Database were examined from October 2007 to September 2018 (Bonine et al., 2020). Claims data for women aged 18–51 years were sorted by demographics and type of treatment, and a Charlson Comorbidity Index score was applied (Bonine et al., 2020). Study data also showed that Black women represented 71% of the patients treated by abdominal hysterectomy and are 65% more likely to be of childbearing age at fibroid removal Bonine et al., 2020). Additionally, despite the prevalence of less invasive treatment options, Black women were 8 times more likely than women of any other race to surgically remove their fibroids via abdominal hysterectomy, the most invasive treatment.

The costs of abdominal hysterectomy as treatment for benign fibroid is expensive, severely impacts Black women, and is an astronomical burden to the health care system (Bonafede et al., 2018). Studies show that abdominal hysterectomy is associated with the most significant economic burden and linked to the highest cost due to postsurgical follow-up and complications (Bonine et al., 2020). As a result of this disparity, Black women bear a greater economic burden than White women because Black women have historically had less access to adequate medical care but are significantly impacted by fibroids.

Treatment Options for Black Women With Benign Fibroids

Researchers do not know why most Black women diagnosed with fibroids choose the most invasive procedure, abdominal hysterectomy, as a treatment option (McClurg et al., 2020). Empirical evidence suggests a racial disparity in Black women's treatment for benign fibroids (Zaritsky et al., 2019). Research shows that 1 in 5 Black women are unaware of treatment options other than a hysterectomy for benign fibroids (Riggan et al., 2021). Black women are 3 to 4 times more likely than women of any other race to receive a treatment plan for an invasive abdominal hysterectomy for benign fibroids (Emerson et al., 2019). In contrast, abdominal hysterectomy for benign fibroids has significantly decreased among women of all other races (Alexander et al., 2019; Callegari et al., 2019). Additionally, research shows that in the United States, laparoscopic hysterectomies have increased by 74%, and robot-assisted hysterectomies have increased by 24% (Alexander et al., 2019). Even with advancements in fibroid treatment, the rate of Black women who receive abdominal hysterectomies for benign fibroids has remained consistently high and has not decreased in over 2 decades. More research, data collection, and awareness are needed to understand what influences Black women to have an invasive hysterectomy for benign fibroids.

The types of fibroid treatment procedures covered by most insurance providers may vary by the specific policy. However, the fibroid treatment procedures discussed in my research became mainstream and covered by insurance in 2006 (Borah et al., 2017). According to the ACOG (2017), while there is no one best way to treat fibroids, the recommended treatment for benign fibroids includes minimally procedures such as laparoscopic myomectomy, robotic myomectomy, endometrial ablation, UAE, magnetic resonance-guided focused-ultrasound surgery, or a hysterectomy. ACOG (2017) strongly recommended that any woman diagnosed with fibroids undergo a thorough evaluation with an obstetrician/gynecologist to help facilitate optimal collaboration with interventional radiologists to ensure that the appropriate, least invasive procedure is recommended based on the woman’s symptoms and reproductive plans for childbearing.

Myomectomy

A myomectomy is a surgical intervention procedure to remove uterine fibroids but preserves a woman’s ability to have children in the future (Danilyants et al., 2020). However, the younger patient at the time of the myomectomy, the more likely the fibroids will reoccur again in the future (Bonafede et al., 2018). According to research, women close to menopause are least likely to have recurring fibroids after a myomectomy (Ali et al., 2018). A myomectomy is the second most performed surgical fibroid treatment after hysterectomy in the United States (Bougie et al., 2019). Approximately 30% of women who undergo a myomectomy will require further treatment later (ACOG, 2021). There is also at least a 10% chance of the myomectomy becoming a hysterectomy due to the size and number of myomas present during surgery

(Hartmann et al., 2017). Additionally, scar tissue from a myomectomy may cause complications for future pregnancies (Hartmann et al., 2017).

Endometrial Ablation

Endometrial ablation is another alternative fibroid treatment procedure. As discussed by Berman et al. (2022), endometrial ablation can be performed using lasers in combination with a hysteroscopy myomectomy. During the procedure, an electrical current is used to destroy the fibroids (ACOG, 2017). The procedure is cost effective as it can sometimes be done in a doctor’s office or outpatient center (Ali et al., 2018). Endometrial ablation is only effective when a few small fibroids are present and best used as an early intervention (Ali et al., 2018). As discussed by Ali et al. (2018), this procedure is not recommended for menopausal women or those with uterus abnormalities.

Uterine Artery Embolization

A UAE or a uterine fibroid embolization is a minimally invasive treatment procedure that does not require a surgical incision, and women can resume their normal activities within a few days (Alexander et al., 2019). UAE is cost effective because no anesthesia or surgery is involved in treatment. UAE treatment can shrink fibroids and preserve the uterus. UAE may damage blood vessels, and a dilatation and curettage procedure may be required to remove dead tissue. UAE may reduce a woman’s chances of bearing children in the future (Stewart et al., 2017).

Magnetic Resonance-Guided Focused UltraSound

Magnetic resonance-guided focused ultrasound (MRgFUS) is a non-invasive fibroid treatment procedure that is not commonly used to treat women who are obese or have been diagnosed with anemia. Many women with fibroids tend to have a higher body mass index and anemia, making them ineligible for MRgFUS treatment (Bonafede et al., 2018). According to ACOG, the procedure is low cost, can be done in a physician's office or an outpatient center, and is very effective, with an 85% success rate (ACOG, 2021). However, MRgFUS may not be a preferred treatment for women seeking to preserve the ability to have children in the future.

Hysterectomy

A hysterectomy is an invasive surgical procedure that involves completely removing the uterus from a woman's body and must be performed by a surgeon (Drayer & Catherino, 2015). After a hysterectomy, a woman can no longer get pregnant. The four most common types of hysterectomy procedures include: (a) vaginal, (b) radical, (c) partial, and (d) total (Gray et al., 2020). A vaginal hysterectomy can only be performed at the stage of early detection of fibroids and involves the removal of the uterus through the vagina (Gray et al., 2020). The vaginal hysterectomy is the least invasive type of hysterectomy (Herrmann et al., 2018). However, vaginal hysterectomies are rarely performed because fibroid treatment involves continuous monitoring via ultrasound surgeon (Drayer & Catherino, 2015). By the time the growth patterns of the fibroid(s) are recorded, and a treatment decision is made, it is typically too late to perform a vaginal hysterectomy (McClurg et al., 2020). A radical, partial, or total abdominal hysterectomy procedure must be performed in those cases (Schwab, 2001).

In the United States, over 600,000 hysterectomies are performed each year (ACOG, 2021). Approximately 90% of those hysterectomies are for the treatment of benign fibroids (Baird et al., 2020). Hysterectomies can be abdominal or open surgery, laparoscopic, or robot-assisted (Herrmann et al., 2018). The two most common hysterectomies performed for benign fibroids are partial and total hysterectomies (ACOG, 2017). Typically, a radical hysterectomy procedure is not performed for benign fibroids. It is typically only performed when cancer is present (Herrmann et al., 2018). A radical hysterectomy includes a procedure known as a salpingo-oophorectomy, removing the cervix, uterus, and connecting tissue, one or both ovaries, and the top of the vagina (Herrmann et al., 2018; Schwab, 2001). A partial hysterectomy is a surgical procedure that involves keeping the cervix but removing the upper portion of the uterus (Schwab, 2001). During a total hysterectomy, the cervix and uterus are removed (Schwab, 2001). A total hysterectomy may also include the removal of the ovaries and fallopian tubes (Schwab, 2001).

Although laparoscopic and robot-assisted hysterectomies are mainstream, covered by insurance, and patients with laparoscopic or robot-assisted hysterectomies have fewer complications and a shorter recovery period, in the United States, abdominal hysterectomies still account for more than half of all hysterectomies performed for benign fibroids (Borah et al., 2017). Black women account for 55% of invasive abdominal hysterectomies for benign fibroids compared to 22% of White women (Alexander et al., 2019). Black women are disproportionately affected due to a higher percentage of fibroids present in the population (Alexander et al., 2019). Black women are most affected, receiving the highest percentage of abdominal hysterectomy procedures as a treatment for benign fibroids compared to White women and women of other races across the United States. Patients who experience invasive abdominal treatments have a higher mortality rate due to complications (Callegari et al., 2019). Research studies of medical records within the same health system show that even when the same type of insurance coverage and symptoms were present, most Black women were treated with abdominal hysterectomy. Therefore, access did not eliminate the disparity.

Black Women's Experience of Hysterectomy

Generally, most hysterectomies for benign fibroids are not an emergency, but sometimes the procedure is medically necessary to manage life-threatening circumstances (ACOG, 2021). Black women are disparately affected by fibroids, and while some researchers suggest genetic and racial differences, significant findings have been unclear (Baird et al., 2020). Across the United States, Black women suffering more severe symptoms and higher rates of abdominal hysterectomies despite advances in less invasive fibroid treatment (VanNoy et al., 2021). The voices of Black women and their lived experiences are still often scantily present in fibroid research (Zota & VanNoy, 2021). Researchers do not know what influences so many Black to make the personal, sensitive decision of choosing hysterectomy as a treatment for benign fibroids (Zota & VanNoy, 2021).

In a study to determine racial differences in treatment, 60 women participated in semistructured interviews about their treatment options. Findings of the study showed that White and Latino women were concerned about the cost preserving the ability to bear children (Gray et al., 2020). The study findings concluded that Latino women were most concerned about recovery length and their work ability. Black women were most concerned about insurance coverage, the cost, preserving their ability to bear children, the length of recovery and the chances of recurring fibroids (Gray et al., 2020). Findings also concluded that Black women often delayed talking to their doctor about symptoms, delayed making treatment decisions and disproportionately expressed concerns about not being able to have children and insurance coverage-related costs (Gray et al., 2020). A follow-up study was conducted 1 year later and found that more half of the Black women had not followed up with their doctor (Gray et al., 2020). The findings of many other studies support that Black women often delay follow-up appointments and treatment decisions and most often chose to have a hysterectomy to eliminate the chance of recuring fibroids. The findings of those studies showed that Black women often considered their family history of cancer or the impact of symptoms on their quality of life ( ). However, it should be noted that even when Black women followed up on treatment and choose to have a hysterectomy, less invasive hysterectomy procedures were not recommended or performed.

Few studies have examined the lived experiences of Black women with hysterectomy for benign fibroids. A study about what shaped 37 Black women's treatment decisions was conducted across age and socioeconomic levels (VanNoy et al., 2021). A thematic analysis revealed that perceptions and fear of cancer influenced Black women's decisions (VanNoy et al., 2021). Community norms about medical mistrust and discrimination also guided the women's decisions against alternative, less invasive treatments (VanNoy et al., 2021). The study concluded that 80% of patients' choices were guided by their social networks and perceptions rather than by their interactions with their physicians (VanNoy et al., 2021). The women were also concerned about which treatment would be covered by insurance, even if it meant selecting the most invasive treatment option. Findings further implicate that physicians should take into consideration the psychosocial experiences of Black women and deliver gynecologic services that are culturally competent (VanNoy et al., 2021). Findings also implicated a larger public health problem. Pollack et al. (2020) supported the findings of VanNoy et al. that on average, Black women wait up to 4 years longer than White women before seeking treatment. Black women who delayed treatment were asked the reason for their decision to delay. They cited the ability to have the choice to have children as a driving factor for the delay in treatment. Black women who decided to have abdominal hysterectomy were asked about their decision (Pollack et al., 2020). Most of the women cited symptoms such as heavy bleeding, headaches, abdominal pain and anemia that seem insurmountable. They also indicated that they were not given any other options except the treatment option to have an invasive abdominal hysterectomy.

Summary and Conclusions

The literature clearly supports a need for the exploration of the lived experiences of Black women who decide to have an abdominal hysterectomy for benign fibroids.

Addressing the gap in the literature by exploring the lived experiences of the population most affect by fibroid treatment disparity can bring to light the multiple realities for the treatment disparity. Additionally, the findings of this study will add to the scant literature to guide the research and development of education and awareness programs specifically for Black women, thereby reducing the treatment disparity.

In Chapter 3, I discuss the chosen methodology for this study. The chosen methodology will show how the lived experiences of the women can further impact fibroid treatment disparity research. Using a qualitative design, I explored each Black woman’s lived experiences with the decision to have an abdominal hysterectomy for benign fibroids. The study will provide a better understanding of what influenced their decisions between diagnosis and the decision to undergo an invasive hysterectomy for benign fibroids (see Cramer & Kapusta, 2017).

Chapter 3: Research Method

Introduction

In the United States, uterine fibroids affect an estimated 26 million women between 15 and 50 impacting all racial backgrounds and socioeconomic levels (Price et al., 2017). Although most women develop fibroids in their early 40s, Black women are more likely than other women to do so at an earlier age; 60% of Black women develop fibroids as early as age 26 compared to 7% of White women (Al-Hendy et al., 2017). More than 85% of Black women are diagnosed with benign uterine fibroids by age 50, compared to 70% of White women (McClurg et al., 2020). Additionally, Black women suffer higher incidences of fibroid-related anemia, pelvic pain, and fertility complications (McClurg et al., 2020). Researchers are still unsure of the reasons for these inequities (Eltoukhi et al., 2014). In this study, I explored the lived experiences of Black women who received the treatment of a hysterectomy for benign fibroids. In this chapter, I will discuss the research method and methodology including the sampling strategy, recruitment, instrumentation, and data collection. I also discuss the research design and rationale and my role in the research. Issues of trustworthiness are also explored in the chapter.

Research Design and Rationale

I chose a qualitative methodology for this study based on the purpose of the research and the research question. A quantitative research design was not appropriate because it would not allow for the collection of in-depth data. A mixed-methods design could have been utilized, but this would have required a larger sample than is practical and made the study too expensive and time-consuming (see Creswell & Creswell, 2017). A qualitative phenomenological design was the best fit to capture the narratives of a population whose voices are barely represented in fibroid research. Such a design allows researchers to apply interpersonal and subjectivity skills to the research process (Patton, 2015).

I used IPA to collect and analyze the data, because it is useful in understanding a phenomenon experienced in a small sample within a shared context (see Flynn & Korcuska, 2018). The decision to have a hysterectomy that precludes the ability to become pregnant is a major life event for women of childbearing age. The IPA methodology enabled me to capture and share the unique experiences and perspectives of the participating Black women who experienced the phenomenon (see Miller et al., 2018). IPA showed the participants' innermost deliberation as they made sense of their decision to have a hysterectomy for benign fibroids (see Behal, 2020). IPA was used to explore the lived experiences of the women from diagnosis to treatment including what influenced them to decide to have an abdominal hysterectomy for benign fibroids, as well as their postoperative experience. IPA is idiographic, psychological, and interpretative in nature and allows the lived experience with the phenomenon to naturally unfold (Behal, 2020). The research question I investigated was, What are the lived experiences of Black women who decided to undergo the procedure of abdominal hysterectomy for benign fibroids?

Role of the Researcher

My role as the researcher was to recruit, interview and interpret the results of each interview. I also served in the interviewer and evaluator roles. In addition to the audio-video recorded interview data, I took notes that included any significant nonverbal responses, intonations, facial expressions, and body language that may have prompted me to ask additional questions based on the present reactions (see Surmiak, 2018) during each Zoom audio-video conferencing interview. I noted my observations of audible and physical data. I acknowledge that I am a Black woman who has experienced the phenomenon of having a hysterectomy for benign fibroids at a young age, and this experience provided a unique perspective and ability to bond with participants in understanding the depth of any emotions tied to the lived experience. However, this did raise the possibility of researcher bias. To address potential bias, I conscientiously documented and bracketed my experiences through journaling. I also used participant validation by having participants review and validate the verbatim transcript and as well as the emerging themes from my interpretation of the data, as recommended by Ravitch and Carl (2016).

Nearly 2 decades later, with many less invasive treatments for benign fibroids now mainstream and covered by insurance, Black women remain the population most often treated with an abdominal hysterectomy for benign fibroids (Lawson, 2017). It is debatable whether my familiarity with the phenomenon fostered potential bias on my part (see Ortlipp, 2008). As the researcher, I was careful to bracket my own experience with the phenomenon in writing prior to conducting the semistructured interviews to mitigate potential ethical concerns. I used a reflective journaling approach to talk about myself and my experiences with the phenomenon. It is essential that the researcher be aware and transparent. I used a reflective journal to address how my lived experiences may have influenced the research, including the presentation of findings (see Ortlipp, 2008).

Methodology

In this study, I conducted IPA open-ended semistructured interviews to capture the experiences of Black women who have undergone a hysterectomy as treatment for benign fibroids. The open-ended semistructured interview questions were designed to facilitate each open, honest sharing and follow-up questions based on the participants' previous responses to uncover additional rich data (see Doll et al., 2019; Lawson, 2017). In this section, I will discuss participant selection logic, the sampling strategy, instrumentation, data collection, and data analysis.

Participant Selection Logic

The participants in this study were Black women, age 18 or older, who had undergone a hysterectomy in the past 16 years, specifically due to a diagnosis of benign fibroids. The period of 16 years was selected for this study because research shows that through surgical advances, less minimally invasive procedures such as laparoscopic and robot-assisted hysterectomies became mainstream after they were covered by insurance in 2006 (Aarts et al., 2015). Due to the uniqueness of the study population, I purposely sampled only women who met the inclusion criteria. The women who participated were expected to share their experiences and commit to completing their role in the study.

Purposeful sampling is the most widely used sampling method in qualitative research. Purposeful sampling allowed me to use my judgment as the researcher to choose the best available, knowledgeable, and willing participants (see Ravitch & Carl, 2016). I chose participants who would provide information-rich experiences about the phenomenon with limited resources in a timely manner (see Benoot et al., 2016).

Fibroids and other reproductive health challenges are common among Black women (Sanei-Moghaddam, et al., 2018). The sample's diversity added richness to the interpretive research (Bethel et al., 2020). Saturation was reached when the information gathered became repetitive and no longer produced new insight into the lived experience (see Braun & Clarke, 2021). I anticipated that saturation would occur between eight to 12 interviews, but I conducted semistructured interviews until saturation was reached. Data saturation is paramount to the qualitative rigor of a study (Bowen, 2008; O'Reilly & Parker, 2012). Data saturation occurs when further information from new participants becomes repetitive (Saunders et al., 2018).

Because phenomenological researchers are interested in individual experiences, I gathered data through in-depth interviews with study participants to gain a full picture of their experience with the phenomenon (see Cuthbertson et al., 2020). In a phenomenological interview, neither the researcher nor the respondent knows what result this interaction between them will generate (Heidegger, 1962). Lived-experience interviews were thematized to understand and illuminate the underlying or unspoken meanings embodied or hidden in lived experiences (see Smith & Osborn, 2015).

Instrumentation

Semistructured interviews were conducted using questions developed around the analysis of the literature reviewed for this study. Since phenomenology is interested in individual experiences, data were gathered through in-depth interviews with study participants to get a full picture of their experience with the phenomenon (see Cuthbertson et al., 2020). In-depth interviews are appropriate to capture each participant's unique experiences, feelings, beliefs, and perceptions about a phenomenon. In-depth interviews are widely used in qualitative research with individuals and group settings (Jamshed, 2014). The semistructured interviews were critical to providing an understanding of each woman's choices, influences, and decisions associated with choosing to have an invasive hysterectomy for benign fibroids.

I used a prescreening form (see Appendix B) to ensure that potential participants accurately represented the target audience in age and race. After confirming their eligibility, I asked participants to complete a demographic questionnaire (see Appendix C) to provide further information about their background. The semistructured interview questions (see Appendix D) provided a guide for my conversation about the participant's lived experience (see Rubin & Rubin, 2012). The concepts explored in the interview questions included participants' beliefs about their choices and decisions, knowledge about treatment options, and the phenomenon (see Patton, 2015). These concepts were drawn from the results of my literature review and the concepts were used to formulate neutral, open-ended interview questions according to the theoretical frameworks. The questions thoroughly addressed the phenomenon of study.

I conducted each interview in a confidential manner that allowed the participant and me to build rapport and trust. I began the interview with personal warm-up questions that enabled the participant to get comfortable before delving into sensitive or uncomfortable topics (see Jamshed, 2014). I utilized probing methods to encourage easy, warm conversation with rich detail. The in-depth interviews enabled me to collect open-ended data and explore each participant's beliefs, thoughts, and feelings about the phenomenon. This method consisted of a dialogue between me and each participant, guided by a flexible interview protocol and supplemented by follow-up questions based on cues, probes, and comments (see Rubin & Rubin, 2012). The semistructured interviews also required establishing trust and rapport with participants and the trustworthiness of the research (see Rubin & Rubin, 2012). The interviews helped me understand each woman's sensitive personal choices and the factors that influenced their treatment decisions (see Creswell & Creswell, 2017).

I kept a robust audit trail to support the process's validity and data. Audit trails included reflective journaling, memos, field notes, preliminary content analysis, and secondary content analysis to ensure accuracy. As Halcomb and Davidson (2006) discussed, successful qualitative interviews hinge on the accuracy of the transcript. It is easy to lose essential facts and meaning when inexperienced in transcribing qualitative data from the source. Reliability of the process and results were included in the audit trails to confirm the accuracy of the lived experience as presented (see Patton, 2015). The interviews were transcribed verbatim using the transcription feature in Zoom and analyzed using hand coding and NVivo QDA software (see Rubin & Rubin, 2012).

Participants were allowed to review and make changes to the transcript to clarify what was said prior to the research's finalization and publishing. No identifying data were present in the stored file, and the data were stored electronically on an encrypted back up drive (see Rubin & Rubin, 2012) that can only be accessed by me and Walden University dissertation committee members. As a requirement of Walden University, data will be kept and stored for a minimum of 5 years.

A field test of the researched developed instrument cannot be conducted without the approval of the Walden University's Institutional Review Board (IRB). However, I solicited the assistance of three friends who fit the study criteria in developing my interview protocol. Their responses were not used in the study. Three sessions with them provided the practical experience to prepare me for the main research study. Additionally, my interview questions were examined by my committee to ensure that they were suitable to capture relevant data and generate answers to the main research question. I used feedback from these sessions to fine-tune my questions and sharpen my interview technique in preparation for my main study.

Procedures for Recruitment, Participation, and Data Collection

The best sources for finding participants who fit the inclusion criteria in my small research study were social media platforms, personal contacts, local community announcement boards, and listservs (Bethel et al., 2020). I have many social media contacts with mutual respect and trust, enhancing recruitment and participant retention for my research study. My recruitment efforts mainly included disseminating a flyer with a call for participants (see Appendix A) on various social media platforms. I also distributed my flyer to my social and professional network and asked them to share the flyer about the study with their social network. To screen potential participants who contacted me, I asked them to complete a 2-min prescreening questionnaire to ensure that they met the inclusion criteria for participation in the study (see Appendix B).

Procedures for Data Collection

For some women, talking about their lived experience with a hysterectomy and what influenced their decision may be emotionally charged as it terminates their ability to bear children. I acknowledge that I had no control over whether a participant will become too emotional or uncomfortable and decide not to complete the interview (see Jamshed, 2014). I informed each participant that the study is voluntary and offered the ability to end the interview at any time if the participant is uncomfortable or emotionally distressed and unable to continue (see Rubin & Rubin, 2012). If a participant was unable to complete the semistructured interview, actions were taken to recruit another participant as described in the recruitment criteria (see Appendix A).

Before beginning the confidential interview, I offered participants the opportunity to select a pseudonym to give anonymity to conceal their identity while preserving the authenticity of their lived experiences (see Patton, 2015). Additional anonymity areas were offered, extending to participant’s biography, city of domicile, mention of physician’s names, medical practices, hospitals, employers, friends, and family members/significant others, etc. (see Surmiak, 2018). IRB consent was necessary. The consent form was created using the standards of Walden University. Informed consent and consent to record the interview were also obtained.

I conducted a semistructured interview about each participant’s lived experience that will delve deeply into personal and sensitive choices and the underlying reasons for the decisions related to the phenomenon (see Creswell & Creswell, 2017). This method typically consists of a dialogue between researcher and participant, guided by a flexible interview protocol and supplemented by follow-up questions, probes, and comments, so proper training will be critical to the interviews’ success (Rubin & Rubin, 2012). The semistructured interviews required warm-up questions to build trust and rapport with participants (see Rubin & Rubin, 2012). The semistructured interviews also required establishing trust and rapport with participants and demonstrating the research (see Rubin & Rubin, 2012). Follow-up questions and probes supplemented the semistructured questions based on conversation flow (see Rubin & Rubin, 2012).

The flow of the interview was an easy natural conversation. I incorporated steps to build a rapport with each woman and tailor the interview flow to each participant’s comfort level. The in-depth interview questions were the same, but the personal exchange differed. I listened for cues from each participant to know when to follow up, move on, or probe for more information (see Rubin & Rubin, 2012). At the end of the interview, I thanked participants and reassured them that their interview was confidential, and no identifying data would be present in the transcript of the interview. I informed participants they would be contacted and given the opportunity to review and make changes to the transcript only to clarify what was said prior to the finalization and publishing of the research. I thanked them for making a difference by contributing their valuable lived experience to add to the missing voices of Black women in fibroid treatment research.

Data Analysis Plan

I used the IPA approach to read each transcript, examine the data, and make sense of it using reflexivity (see Castleberry & Nolen, 2018). I used a six-step process to create the interview summary: verbatim transcription and the summative techniques of audio-video conferencing via Zoom, reflective journaling, listening, preliminary content analysis, secondary content analysis, and thematic review (see Halcomb & Davidson, 2006). This six-step process optimizes the credibility of the interviews and the data collected and analyzed (Shenton, 2004). I provided rich, detailed findings from the study that will offer transferability to some degree (see Shenton, 2004). Additionally, I ensured the dependability of the research by preserving field notes, memos and journaling the rich details of the data collection process (see Patton, 2015). The notes include all aspects of data collection, including plans, changes in plans, missteps, and lessons learned along the way (see Smith & Firth, 2011).

I looked for emerging themes, significant patterns, and concepts across the transcripts. I read and re-read a single transcript to immerse myself in the data. I recorded emerging themes in the margin of the transcripts. I grouped emerging themes noting how they relate. I bracketed my own biases and any preconceived notions from the previous transcript and then moved to the subsequent transcript and completed the same steps discussed above (see Behal, 2020). I repeated this process until I completed all the transcripts. This process took several weeks as I looked for emerging patterns and themes across all transcripts and gained a deeper understanding of each woman's experience.

As I concluded the analysis, I used the interconnectedness of each question to the study's theoretical framework to draw further inferences about the data. I examined the data to identify the interconnectedness with the HBM and emerging themes around the women's perceptions that provide insight into understanding their feelings and perceptions about their diagnosis and what finally triggered them to decide to have a hysterectomy for benign fibroids (see Herrmann et al., 2018). I also looked for the interconnectedness between the SEM and how the women's surrounding environment shaped their decision-making process, perceptions, and lived experience to understand how their choices were influenced (see Bogardus et al., 2019). The focus of the research question on eliciting the participants' perspectives about the phenomenon to identify themes to the existing scant body of research (see Cuthbertson et al., 2020). I aimed to describe the treatment options that the women were given as accurately as possible to what led them to the decision to undergo the most invasive procedure for benign fibroids (see McClurg et al., 2020). To ensure the rigor, reflection, and reflexivity of the data, in addition to bracketing, participant validation was used to ensure the intent and interpretation of the data are valid (Behal, 2020).

I used both hand-coding and the QDA software NVivo for the analysis of the data. The software was valuable in quickly analyzing data from multiple interviews (see Rubin & Rubin, 2012). Additionally, the use of the QDA software brought the desired reliability and validity to the results (see Rubin & Rubin, 2012). I used the process of hand coding to immerse myself in the data further, reading and re-reading the transcripts for emerging themes. The mix of QDA software and hand-coding provided a system of checks and balances to ensure the reliability and validity of the data. As accurately as possible, I described the treatment options that the women were given, their choices, and what influenced their choices and led to their decision to undergo the most invasive procedure for benign fibroids (see Ravitch & Carl, 2016). Analysis of the participants' lived experiences will add to the existing scant body of research on the phenomenon (Cuthbertson et al., 2020).

Issues of Trustworthiness

Proper coding gives credibility to the research (Rubin & Rubin, 2012). As Behal (2020) discussed, there is a six-step process to creating the interview summary: (a) transcription and the summative techniques of audio-video recording, (b) reflective journaling, (c) listening, (d) preliminary content analysis, (e) secondary content analysis, and (f) thematic review. This six-step process optimizes the credibility of the interviews and the data collected and analyzed (Behal, 2020). I provided rich, detailed findings from the study that offer transferability to some degree (see Rubin & Rubin, 2012). However, it should be noted that transferability is contextual as the results can only be generalized to a similar population. I ensured the dependability of the research by preserving field notes, memos and journaling the rich details of the data collection process (see Lemon & Hayes, 2020). The notes include all aspects of data collection, including plans, plans changes, missteps, and lessons learned along the way (see Lemon & Hayes, 2020). I further demonstrated that research findings are the lived experience of the participants by preserving audit trails with field notes, journaling of coding methodology, and emerging themes.

Credibility

Participant validation was used to establish the credibility and trustworthiness of the data. This technique also ensures the data's accuracy, credibility, transferability, and validity. Conducting semistructured interviews to the point of saturation allowed all perspectives about the phenomenon to emerge from multiple sources (see Belotto, 2018). Each woman's unique lived experience and perspective about the phenomenon provided triangulation of the data from various points of view. Understanding the phenomenon from multiple sources is a well-known qualitative test of validity to establish the credibility of the data (Lemon & Hayes, 2020).

Transferability

The different perspectives of a purposeful sample generalize the transferability of the findings to establish the likelihood of obtaining the same data in context to the phenomenon (Schloemer & Schroder-Back, 2018). I provided a detailed description of the population of study so that the study can be replicated with women who had a hysterectomy for benign fibroids in the past 16 years and identify as Black or African American in other geographic locations, times, and places. The detailed descriptions provided in the Research Design and Rationale and Methodology sections further enhance the transferability of the research within context. However, if transferred to a different context, the criterion for transferability lies with the researcher who wants to transfer the results of my research (see Ravitch & Carl, 2016).

Dependability

A dependability audit of the research will reveal any errors that I made in the conceptualization of my study, data collection, findings, and results. I used audit trails to establish that the study met qualitative credibility and transferability standards and to ensure that the trustworthiness of the research is not diminished (see Lemon & Hayes, 2020; Schloemer & Schroder-Back, 2018). Audit trails for this study include reflective journaling, memos, field notes, preliminary content analysis, and secondary content analysis to ensure accuracy (see Castleberry & Nolen, 2018). I used standard qualitative data collection methods, practices, and instruments to ensure that results can be trusted, and the study can be replicated.

Confirmability

The confirmability of the results of my research was enhanced using various audit trails to ensure that findings are based on data collected from study participants and not based on my experience with the phenomenon (Muthli & Singh, 2022). My reflection and journal notes after each interview confirm and document my efforts to remain unbiased as the researcher and interviewer and validate that the data collected during each interview is that of the participant.

Intercoder and Intracoder Reliability

The coding of qualitative research can be challenging due to the open-ended nature of the questions. In coding each interview, interview notes, audio-video recordings, and transcripts, hand coding, and NVivo was used to create codes and identify patterns. Using both hand coding and NVivo techniques enhanced the reliability of the data (see Belotto, 2018). Hand coding further enhanced the study by ensuring that rich data provided by any emotions and tone inflections present are interpreted and represented when coding (Belotto, 2018).

Ethical Procedures

The Walden University's Office IRB ensures that all dissertations comply with the rigorous ethical stands of the university in addition to United States' Federal Regulations governing research (Walden University, 2019). Prior to beginning recruitment and data collection, my research must undergo internal ethics review by Walden's IRB. I could proceed with the research study until Walden's IRB approved my application. I acknowledge that a hysterectomy is a sensitive, personal decision so participating in this study may have involved some risk of emotional discomfort, which may become challenging. As a researcher, I ensured that my participants were protected from physical and psychological harm, especially given the topic's sensitive nature. I made participants aware that the study was voluntary, and they could end the interview at any time. Participants were not harassed or held liable for withdrawal or inability to complete the semistructured interview. As the researcher, I obtained consent to conduct and audio-video record each interview.

Summary

In this chapter, I described the research design, rationale, proposed methods of the study, and the interconnectedness of the research question. In my research, I used foundational theories that are tested, proven, and supported by empirical evidence to better understand the lived experiences of Black women. The research addresses the gap in the literature to better understand why Black women decided to undergo a hysterectomy for benign fibroids (see Sengoba et al., 2017).

Using a phenomenological approach, my study may provide a better understanding of what influenced their decision-making process in deciding to undergo an invasive hysterectomy for benign fibroids (Cramer & Kapusta, 2017). In Chapter 4, I will present the results and analysis of the semistructured interviews. Chapter 5 will present the researchers interpretation and findings of the data and conclusions of the study.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to explore the lived experiences of Black women who decided to have an abdominal hysterectomy to provide a better understanding of the sensitive, personal choices and factors that influenced their decision to undergo this most invasive treatment for benign fibroids. Although Black women are the population most likely to have an abdominal hysterectomy for benign fibroids, fibroid treatment research is barely reflective and inclusive of their voices (Baird et al., 2020). In conducting this study, I strove to add the voices of this population to the research.

I sought to answer the following research question: What are the lived experiences of Black women who decided to undergo the procedure of abdominal hysterectomy for benign fibroids? In this chapter, I present the study's findings organized by theme with supporting tables and quoted responses to the semistructured interview questions, along with supporting subthemes. The chapter also includes the demographics of participants and discussion of the data collection and analysis procedures. After presenting evidence of trustworthiness, I provide a detailed summary of the results and a brief transition to Chapter 5.

Setting

After receiving IRB approval (no. 12-16-22-0867490), I commenced recruitment. My first step, on December 16, 2022, was to send an email about my research study with the recruitment flyer attached to my social network. I asked recipients to immediately share the flyer with their social network via email and social media. I also asked them to specifically share the email with any Black woman they thought might meet my study's inclusion criteria. I posted the study flyer to my personal LinkedIn and Facebook pages. Upon receiving email notification of a potential participant's interest, I emailed the prescreening questionnaire (see Appendix B) requesting that the potential participant reply to the email with answers to the three prescreening questions. Once the answers to the prescreening questions were received, if a woman did not meet the prescreening criteria, I sent her an email thanking her and explaining why she could not be included in the study. If a woman met the prescreening criteria, I sent the IRB-approved consent form to her via email and asked that she read the consent form and respond by email with the words "I consent." The email also contained a link to my calendar where the potential participant could schedule a 60-min audio-video conferencing interview according to their availability. The email also advised that no scheduled interviews would be confirmed if the "I consent" email response was not received.

I collected data for my study using the Zoom videoconferencing platform. Zoom is a secure cloud-based platform that is easily accessed through a unique meeting link for data collection (Sah et al., 2020). Upon confirmation of the selected interview date and time, a unique Zoom link was issued, and a reminder was sent 24 hr and then again 2 hr before the interview. The email reminded participants to be available in a quiet private setting for 60 min. I manually set Zoom to video record and transcribe each interview. After a brief introduction, each interview was recorded in real-time using the Zoom "start recording and transcription" feature and immediately transcribed by Zoom once the interview ended. A backup sound recorder application with a sensitive external microphone was also used to ensure that the interview was captured. Before the interview, I did not share my personal history related to the phenomenon to prevent unintentional influence on answers to the research question. All study participants were unknown to me before recruitment for this research study. They were not influenced by any organizational or personal conditions. In addition to a selected pseudonym, each participant was assigned a unique identification and referred to as Participant 1 (P1), Participant 2 (P2), and so forth (see Table 1).

Demographics

Fourteen participants met the eligibility requirements by self-identifying as a Black or African American woman, age 18 years or older, who had received an abdominal incision and hysterectomy for benign fibroids in the past 16 years (2006 - 2022). Participants were asked six demographic questions (see Appendix C) that provided insight into their experience with abdominal hysterectomy. As detailed in Table 1, participants were between the age of 38 and 68 at the time of the semistructured interviews. Only women who met the inclusion criteria were chosen to participate. Each participant provided a pseudonym to remain anonymous and was provided with a numeric participant identification.

Table 1

Participant Demographics

Participant	Pseudonym	Age at interview	Year first diagnosed with benign fibroids	Year of abdominal hysterectomy for benign fibroids	Age at hysterectomy	Number of birth children

P1	Jessica	55	1996	2008	40	0
P2	Bola	44	2014	2018	39	0
P3	Sage	52	2005	2015	43	0
P4	Candi	39	2014	2022	39	1
P5	Cassie	57	2007	2008	42	3
P6	Kima	47	2009	2009	33	0
P7	Karley	51	2011	2016	44	1
P8	Mimi	68	2005	2008	54	0
P9	Linda	53	2007	2013	43	0
P10	Melanie	42	1999	2017	36	1
P11	Nikki	38	2018	2019	35	0
P12	Gem	45	2015	2018	40	2
P13	Crystal	46	2003	2022	46	2
P14	Lynn	45	2013	2016	38	1

Data Collection

The data collection period for this study was from December 2022 through February 2023. I interviewed a total of 14 women. Each participant interview was scheduled for 60 min, including introductions and a review of the interview guide with each participant. A review of the Zoom audio-video recordings and transcripts shows that 12 interviews lasted up to 48 min, and two were 60 min each. I conducted the interviews via Zoom from the privacy of my home office. Before the interview, email communication was sent to all participants encouraging them to find a quiet private setting to ensure their confidentiality and comfort in sharing their personal, sensitive lived experiences. All participants were asked the same interview questions (see Appendix D). Follow-up questions were based on probes for clarity when I did not fully understand a given response, when the answers were ambiguous or vague, or when I wanted to obtain more detailed or specific information, as recommended by Jamshed (2014). Because all interviews were conducted via Zoom, I was able to capture each participant’s unique experiences, feelings, beliefs, and perceptions about the phenomenon of interest.

At the beginning of each interview, I greeted each participant and read the interview guide script to them. Participants were assured that there were no right or wrong answers and that their interview would be kept anonymous. Participants were encouraged to share their true feelings, perspectives, and lived experiences with the phenomenon. Participants were reminded that their participation was voluntary and that they could stop the interview at any time. I then posed six demographic questions (see Appendix C) to each participant and provided them a pseudonym. After I captured the participant's demographic data and pseudonym on a separate demographic sheet, I asked any additional questions. I then advised that with permission, I would begin the Zoom audio-video recording of the interview. No participant declined the audio-video recording of their interview.

Participants comfortably shared their lived experiences with their invasive abdominal hysterectomy, expressed emotions and provided insights into the thoughts, perspectives, influences, choices, and decisions that affected their daily reality. Although all participants seemed comfortable, a few expressed sadness and ongoing doubt about their decisions but did not show signs of distress. When participants expressed sadness, after listening, I asked if they would like to stop the interview based on their feelings or if they would like to continue the interview. Those participants expressed that they were okay and desired to continue sharing their stories about their experiences to add to the research with the hope that it will be helpful to other women who are faced with the same decisions.

After each interview, participants were thanked, debriefed, issued a $15 e-gift card in appreciation, and reminded about the participant validation process involving their validation of the verbatim transcripts and emerging themes. Transcripts were reviewed and hand-coded upon the completion of 11 interviews. Common themes began emerging from participant responses. Evidence of data saturation was achieved after 11 interviews, as no new themes or patterns emerged from the data. Three additional interviews were scheduled to see if new themes would emerge. Upon further thematic review and hand-coding of all 14 transcripts, I re-confirmed that data saturation had been reached. No new knowledge could be learned from the participants' responses, and no new themes emerged (see Braun & Clarke, 2019). Participants were provided a copy of their verbatim transcripts and emerging themes to ensure I understood what each participant meant as I conducted thematic reviews of the transcripts. None of the participants expressed dissatisfaction with their transcripts or emerging themes. No unusual circumstances were encountered when collecting data, and there were no variations in data collection from the plan presented in Chapter 3.

Data Analysis

Data analysis for this study included a combination of hand-coding and NVivo Version 12 to provide a system of checks and balances to ensure the reliability and validity of the data. I used IPA to analyze data. This form of analysis enables a better understanding of the phenomenon experienced in a small sample within a shared context (see Castleberry & Nolen). Data analysis included the following six-step IPA process for each participant interview: a review of the recording of the audio-video interviews via

Zoom, a review of the verbatim transcripts and making notes in the margins, a review of field notes, a preliminary content analysis, secondary content analysis, and thematic review. The data analysis included a review of verbatim transcripts and audio-video of each interview multiple times, to allow the lived experience with the phenomenon to naturally unfold as I developed initial hand coding. Keeping in mind that a hysterectomy ends a woman’s ability to have children and is a personal, sensitive decision that can become emotionally distressing and uncomfortable to discuss, my field notes provided important additional context to the lived experience and added depth to the qualitative findings.

As the transcripts were reviewed, themes emerged and as I re-read each transcript. I color-coded participant statements relevant to these emerging themes. I verified the meaning of each theme against the verbatim statements and contextual elements in the transcripts to ensure I was interpreting the data correctly. I categorized the themes in Microsoft Excel along with supporting participant responses from the verbatim transcripts and field notes. As I did so, I condensed redundant themes and eliminated statements that did not provide a further understanding of the lived experience.

NVivo Version 12 software was used to ensure the validity and reliability of hand coding and analysis. The use of NVivo involves several steps, as described by Braun and Clarke (2018). The coding structure involves short verbatim phrases, paragraphs, and sentences from each transcript that express common thoughts or ideas. Codes were formed based on common phrases, paragraphs, or sentences as recommended by Belotto (2018), and any data unrelated to the research question were removed and stored in a separate file. The codes were labeled based on how the data were related to the research question. Every code was labeled to represent potential themes expected to emerge from the data. I started the coding process by referring to the descriptive texts that emerged. Codes belonging to each string of descriptive text were identified. A new code was added to the coding scheme if a descriptive text did not have a matched predetermined code (Belotto, 2018). Overall, several codes emerged from the data, and themes were then developed. Categories were formed from codes that were alike, and these categories formed the themes used to answer the research question. The final themes were: (a) invasive abdominal hysterectomy was the only treatment recommended, (b) women’s desire to have children influenced their treatment decisions, (c) social supports influenced treatment decisions, (d) severity of symptoms influenced treatment decisions, (e) family history influenced treatment decisions (f) emotional stress about the recommended treatment and/or overall treatment plan was common, (g) lack of knowledge about the postsurgical effects was experienced by a few, and (h) the postsurgical psychosocial impact was the hardest part of treatment. The frequency of each theme reported by participants is shown in Table 2.

Table 2

Frequency of Themes as Reported in Participant Responses

Theme	Participant													
	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14
Invasive abdominal hysterectomy was the only treatment recommended	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Women’s desire to have children influenced their treatment decisions	x	x	x	x	x					x	x		x	x

Social supports influenced treatment decisions	x	x	x		x		x			x	x	x	x	x
Severity of symptoms influenced treatment decisions	x	x	x	x	x		x	x	x	x	x		x	x
Family history influenced treatment decisions						x						x		
Emotional stress about the recommended treatment and/or overall treatment plan		x				x		x		x	x			x
Lack of knowledge about postsurgical effects	x	x			x			x				x		
Postsurgical psychosocial impact was the hardest part of treatment		x				x		x			x	x		x

I then grouped the eight dominant themes into three categories based on the similarity of characteristics or central ideas taken from the participants’ verbatim transcripts. The categories and themes were grouped to tell a textual story based on the combined lived experiences of the participants (see Castleberry & Nolen, 2018). One theme was further organized into a subtheme to bring clarity to the data as shown in Table 3. In the Results section of this chapter, each of the themes and subthemes are described in detail and tied to the verbatim quotes to support each finding. There are no discrepant cases, and the data will be presented by theme.

Table 3

Categories, Themes, and Subthemes

Category	Theme	Subtheme
Category 1: Factors Contributing to Treatment Decision	Theme 1: Invasive Abdominal Hysterectomy was the Only Treatment Recommendation	Subtheme 1-1: Unaware of Alternatives
		Subtheme 1-2: Aware of Alternatives

Category **2**: Influences on the Choice to Have an Invasive Abdominal Hysterectomy	Theme 2: Women’s Desire to Have Children Influenced Treatment Decisions Theme 3: Social Supports Influenced Treatment Decisions Theme 4: Severity of Symptoms Influenced Treatment Decisions Theme 5: Family History Influenced Treatment Decisions
Category 3: Presurgical and Postsurgical Impacts	Theme 6: Emotional Stress About the Recommended Treatment and/or Overall Treatment Plan Theme 7: Lack of Knowledge About Postsurgical Effects Theme 8: Postsurgical Psychosocial Impact was the Hardest Part of Treatment

Evidence of Trustworthiness

Trustworthiness is understood as the level of confidence in data and interpretation and the rigor and methods utilized to ensure the quality of a given research study. The trustworthiness of this qualitative study is established by the study’s credibility, transferability, confirmability, and dependability. The following six-step process for optimizing the trustworthiness of the study was used: (a) a review of the recording of the audio-video semistructured interviews, (b) a review of the verbatim transcripts and making notes in the margins, (c) a review of field notes, and (d) conducting preliminary content analysis, (e) secondary content analysis, and (f) thematic review (see Castleberry & Nolen, 2018). The discussion about credibility, transferability, dependability, and confirmability established the trustworthiness of this study.

Credibility

Participant validation was used to establish the credibility and trustworthiness of the data. This technique also ensures the data's accuracy, credibility, transferability, and validity. Conducting semistructured interviews to the point of saturation allowed all perspectives about the phenomenon to naturally emerge from multiple women (see Belotto, 2018; Braun & Clark, 2021). Understanding the phenomenon from multiple sources is a well-known qualitative test of validity to establish the credibility of the data (Lemon & Hayes, 2020). Each woman's perspective is unique to their lived experience and provided triangulation of the data from various points of view. Additionally, audit trails were used and included reflective journaling, memos, field notes, preliminary content analysis, and secondary content analysis to ensure accuracy (see Castleberry & Nolen, 2018).

Transferability

Transferability is the second significant aspect of trustworthiness. It is understood as the generalizability of the study findings and the ability to apply the findings to other contexts and participants (Lemon & Hayes, 2020). The use of purposeful sampling to choose available participants who could provide rich, detailed experiences in a timely manner ensured with specificity that the data could be representative of Black women who have lived experiences with the phenomenon (Korstjen & Moser, 2018). Rich, detailed data were provided from the interviews, providing an in-depth understanding of the lived experiences of Black women who decided to have an invasive abdominal hysterectomy for benign fibroids.

Dependability

Dependability is utilized in demonstrating or measuring the reliability and consistency of the study's results. Dependability was established using standard qualitative data collection methods, practices, and instruments associated with qualitative data collection, such as audit trials. According to Nowell et al. (2017), an audit trail refers to a transparent description of the steps taken in a research study from the beginning until the findings are reported. For this study, dependability was established by using audit trials, which included reflective journaling, field notes, preliminary content analysis, and secondary content analysis to ensure accuracy (see Castleberry & Nolen, 2018). Notes included all aspects of data collection, including lessons learned along the way (see Smith & Firth, 2011).

Confirmability

The confirmability of the study refers to the neutrality of the research findings (Amin et al., 2020). The study focused on the lived experiences of Black women with the decision to have an invasive abdominal hysterectomy for benign fibroids. I bracketed my experience with the phenomenon by taking field notes during each semistructured interview and writing reflective and journal notes to ensure my efforts remained unbiased (see Korstjens & Moser, 2018). Reviewing the audio-video recording of the interviews multiple times confirmed the field notes were valid and based on each participant's interview, not my biases, opinions, or experiences (Shenton, 2004). Additionally, the confirmability of the study was upheld by validating that the themes portrayed the responses of the participants utilizing the six-step process and in addition to the multiple sources of data collected from participants during the process (i.e., audio and video recording, verbatim interview transcripts, field notes). Overall, providing a rich, detailed audit trail of the data collection and analysis, along with the use of a qualitative research design and methodology common in peer-reviewed journals, established confirmability that the research findings accurately reflect the participants' responses.

Results

I explored the lived experiences of Black women who decided to have an invasive abdominal hysterectomy for benign fibroids. To do so, I conducted semistructured interviews with participants (see Appendix D for the questions). In this section, the results of the data analysis are organized by the themes that emerged from the interview data coupled with the supporting evidence or quotes.

Theme 1: Invasive Abdominal Hysterectomy was the Only Treatment Recommended

For the 14 women interviewed, an invasive abdominal hysterectomy was the only treatment recommended by their doctor.

Subtheme 1-1: Unaware of Alternatives

Nine of the 14 women interviewed were recommended to have an invasive abdominal hysterectomy and were unaware of alternative treatments. The women also stated that their doctor did not discuss or educate them about other treatment options or why other treatments were not a good fit. For example, P1 stated,

> …now we have all these other options for women with fibroids, but I didn't even have those options offered or discussed or come up in a conversation. …looking

> back, those conversations should have happened so I could be made aware of why or why not each option would not fit me for treatment. … I should have been aware of that information even if it wasn't best for me. She should have let me know.

Similarly, an abdominal hysterectomy was recommended for P2, who stated,

> My doctor said that it was best for me to have a hysterectomy. He didn't really say much else except let's take care of this immediately and that the nurse would give me some information so that they could schedule the surgery. I wasn't offered any choices or explanations about possible options even to simply explain why they were not good options for me.

P5 reported, "She (the doctor) didn't discuss much except to say that I needed a hysterectomy asap, that's all she said about any type of treatment or cure, just you need a hysterectomy." Several participants expressed surprise or regret about this lack of choice. For example, P8 stated,

> I was very surprised when she said that I needed to have a hysterectomy. …maybe we could have tried some other treatment if she had caught the change in size earlier, but none of that was discussed. She didn't even explain anything about the hysterectomy.

Some women simply accepted the doctor's recommendation as being a solution to their problem. For example, P9 stated,

> She is the expert, right? All she said was a hysterectomy and I said okay. She did not mention any other type of treatment. I had already been through so much with

> being anemic and exhausted all the time because of the heavy bleeding and the whole nine yards. I just wanted to move forward with my life. She did not explain anything, and I trusted her at the time.

Likewise, P11 also accepted the doctor's recommendation as a solution. She stated,

> … my doctor didn't give me many options and I was surprised. My options were to have a baby or have a hysterectomy. I wasn't in a relationship at the time, and I wasn't about to just go out and have a baby with a stranger. I don't know when options like embolization and other treatments came to the forefront, but she didn't give me those options. But I was in so much pain that I just moved forward with the hysterectomy.

Others were more questioning and rejected the doctor's recommendation at first. P10 was diagnosed with fibroids at age 24 and only offered the treatment of abdominal hysterectomy but, because she was young and wanted to have children, she decided not to have it; she lived with the symptoms for over 12 years, during which she suffered two miscarriages and then finally had a baby. Only then did she proceed with the recommended abdominal hysterectomy at age 36. She stated,

> My doctor recommended that I have a hysterectomy, but I just decided that I would deal with the heavy periods, and I just stopped thinking about the fibroids. I didn't have children and just could not deal with the thought of a hysterectomy. That was the only treatment that she kept talking to me about, hysterectomy. … every time a gynecologist brought up the fibroids and hysterectomy, I let them know that they were not really bothering me that much even though I was in a lot

> of pain.

P13 also rejected the doctor's recommendation at first. P13 stated,

> …a hysterectomy was the only treatment mentioned. So, in 2012 when my daughter was two, my doctor mentioned the hysterectomy again. Once again, I had already made up my mind that I would just deal with the pain and heavy bleeding. So, for many years I just dealt with the pain and bleeding and pushed the hysterectomy to the back of my mind.

P13 had an invasive abdominal hysterectomy in 2022. Likewise, P14 stated,

> My doctor informed me at that point that I had some fibroids and that there are no other options that are really better for me. She said let's get this taken care of right away so you can move on with your life. That's all she said and didn't really go into any details about options. She only talked about abdominal hysterectomy, and she showed me where they would make a bikini cut for the surgery but did not mention other options. My thoughts were only about trying to get pregnant immediately. I decided to delay the hysterectomy and try to have a baby. When I got pregnant it was rough and my daughter was born prematurely because of the fibroids. I went ahead and had the hysterectomy after that.

Subtheme 1-2: Aware of Alternatives

Five of the 14 women interviewed were recommended to have an invasive abdominal hysterectomy as treatment but were aware of alternative treatments, and initiated discussions with their doctors about alternatives. Several of the women discussed the alternatives, but their doctors still ultimately recommended the treatment of invasive abdominal hysterectomy and cited various medical reasons. Some of the women who were aware of the alternatives had the recommended treatment because having a baby was not an important factor in their life. For example, P3 who never got pregnant and had an abdominal hysterectomy in 2015 stated,

> In 2005 my doctor recommended that I either try to have a baby or have a hysterectomy. At the time I was only in my 30s and I was surprised that she didn’t give me any options. At the time I was working in the medical field and was familiar with some of the other procedures like embolization, but I didn’t really press the issue in discussing it with her. At the time I was doing okay with the fibroids, and I just figured that if I got pregnant and had a baby, I would have the hysterectomy after, but it is not like having a baby was a strong goal of mine.

For some women, their doctor indicated that due to the size and number of fibroids, the best treatment option was the recommended invasive abdominal hysterectomy. Although feeling unsure about their doctor’s recommendation, they still decided to have the recommended treatment. For example, P7 stated,

> My doctor wanted to cut my stomach to do a hysterectomy. My daughter did some research and found out that there were a lot of risks involved with that. She told me that they can do a hysterectomy via laser surgery and the recovery time is quick with fewer complications. I was a little irritated that my doctor did not bring up the subject of other options to me, I had to bring it up to her. I asked her about other ways of treating fibroids, and I specifically asked her about laser surgery and not cutting my stomach. She said that she did not bring those options up to

> me because they would not be a good fit for me. She said that I had to have the abdominal hysterectomy because of the number of fibroids and that it wasn't wise to do laser in that case. She only started explaining everything to me when she realized that I knew something about other treatments. She was concerned about the size and number of fibroids, so I went ahead and had the abdominal hysterectomy. I guess that was best for me.

Similarly, after discussing alternative treatment options with her doctor, P4 was told that an abdominal hysterectomy was the best-fit treatment due to the size and number of fibroids. At first, P4 rejected her doctor's recommendation and decided to delay treatment to focus on trying to conceive another child. However, severe symptoms led her to eventually have the recommended treatment. Likewise, both P6 and P12 were only given the recommended treatment of abdominal hysterectomy by their doctor. Both women were aware of alternative treatment but decided to move forward with the recommended abdominal hysterectomy after assessing their risk for cancer. P6 stated,

> I was diagnosed with fibroids shortly after my mom died of cervical cancer. On top of that, shortly after that my sister was also diagnosed with fibroids and had to do a biopsy and they found suspicious cells like it could be cancer. My doctor had not mentioned alternative treatment options, but I had done some research and was going to ask her about laser surgery. But after the news about my sister, I decided to just have the abdominal hysterectomy. I just didn't want to take any chances with cancer. I felt that if everything was taken out then I don't have to worry about it, so I never got the chance to ask my doctor about other treatment

> options and she did not mention any to me.

Similarly, P12 considered fibroids removal via laser surgery, but the severe symptoms and her assessment of risk due to her family history of cancer influenced her decision to forgo discussing laser treatment with her doctor and move forward with the recommended abdominal hysterectomy. She stated,

> I assumed that I could not get laser surgery… that’s why my doctor didn’t mention it. So, I guess there was nothing to discuss with the doctor. I was very worried about cancer because that runs on my Mom’s side of the family. I was tired of the constant pain, bleeding, and living in fear that the fibroids could become cancer. I just moved forward with the abdominal hysterectomy since that was the only option.

Theme 2: Women’s Desire to Have Children Influenced Their Treatment Decisions

Many of the women shared that they first considered whether they wanted to have one or more biological children in the future because once a hysterectomy is performed, they would no longer have the ability to get pregnant. Five of the 14 women stated that their treatment decisions were not influenced by the desire to have children.

Several other participants desired to have a child and initially rejected their doctor’s recommendation and delayed treatment to try to conceive but were not able to due to the fibroids. For example, P1 who has no children stated,

> I was first diagnosed with fibroids in my early 20s and I had a myomectomy to remove the fibroids. A few years later I got married and we were trying to have a baby but that wasn't going well. We learned that the fibroids had returned. We

> wanted to try to wait and see if I could at least manage to get pregnant and have one child. …I tried but sadly, that never happened for us. I ended up having to undergo an abdominal hysterectomy.

Likewise, P2 who has no biological children initially decided to reject the recommended treatment to try to conceive. She stated,

> …so I decided to try to get pregnant and we tried for about a year after finding out about the fibroids but it did not happen because the fibroids were causing problems. Eventually, I had to make a decision because I was in so much pain, so I did the hysterectomy.

P4 who already had one child at diagnosis also stated,

> Like I said, during that time I was trying to focus on getting pregnant. Eventually, I had to do something because the bleeding was quite excessive and I was in severe pain all the time. ...I went ahead and did the hysterectomy in late last year, 2022 when everything opened back up from the pandemic.

P11 who had no children also considered rejecting the recommended treatment to try to conceive. She stated,

> I really had to process whether or not I could deal with the pain long enough to try to have a baby. I just was torn because my wedding was in a few months and being in pain and bleeding all the time could ruin my wedding but in my mind I was thinking that not being able to have at least one child could ruin my marriage, or so I thought at the time. But I was in so much pain that I ended up having the hysterectomy.

Other women who decided to reject the recommended treatment because of their desire to have children were successful in conceiving. For example, P10 shared,

> I wanted to try to have at least one child but my doctor told us that a fetus would not survive because of the lack of space in my uterus. So like I just can't say it enough, God had other plans. We decided to try anyway and had 2 miscarriages. Over a 2-year period, I fought to get pregnant again and was on bed rest when I got pregnant the third time. It was rough but worth it. …but I understand that my experience is not the norm, but I am truly grateful.

Likewise, P13 who was successful in giving birth to 2 children after her doctor recommended the treatment of abdominal hysterectomy stated,

> I had a myomectomy to remove fibroids and then was diagnosed with fibroids again a few years later. When the fibroids returned, my doctor recommended that I undergo an abdominal hysterectomy. By that time I was married and having difficulty getting pregnant so when I went to see a doctor and the examination revealed that the fibroids had returned. The doctor said that since I had fibroids removed before, this time I should consider having an abdominal hysterectomy. A hysterectomy was the only treatment mentioned and he mentioned that was the only way to keep the fibroids from growing back. I was still pretty young so I tabled any discussion about having a hysterectomy and my husband and I continued to try and eventually I got pregnant with our son so the fibroids or a hysterectomy became not a big concern for me. Two years later, I got pregnant with our daughter so once again, the fibroids just were not a big concern for me. I

> kind of delayed or forgot all about the fibroids. I completely pushed it out of my mind. Then, in 2012 when my daughter was two, the doctor mentioned the hysterectomy again. Once again, I had already made up my mind that I would just deal with the pain and heavy bleeding. So for many years I just dealt with it and pushed the hysterectomy to the back of my mind until 2022.

P13 rejected the recommended treatment for approximately 15 years and had two children after her doctor recommended the treatment of abdominal hysterectomy. P13 had an abdominal hysterectomy in 2022. She stated, “The fibroids began to severely affect my quality of life so I did it. P14 also initially rejected the recommended treatment of abdominal hysterectomy and had a child. She stated,

> After my doctor said that I needed to have a hysterectomy, I heard her but decided that I would try to see if I could get pregnant. So, I decided not to have the hysterectomy right away. My only thoughts were only about trying to get pregnant immediately. When I got pregnant it was rough and my daughter was born prematurely because of the fibroids. I had gone through a lot to get to that point, but my daughter was just fine. I risked it all for her. I went ahead and did the hysterectomy after that.

Other women decided to initially reject or delay the recommended treatment to consider their options. For example, P3 who had no children and had an abdominal hysterectomy 10 years after being diagnosed with fibroids stated,

> My doctor recommended that I either try to have a baby or have a hysterectomy. …for like 10 years I had some pretty long-term relationships, but just never got

> pregnant. I also told myself that if I didn't have a child by the time, I was like 42 or 43, then I wasn't going to worry about it and would probably do the hysterectomy. During that 10-year period, I just never got pregnant. I was having heavy, really, really heavy periods. Sometimes my period would last for 3 weeks and stop for a week and then start again.

P5 who already had three children stated,

> I took a few months to think about whether or not I wanted to have more children before I made my decision. About 6 months later I thought to myself well I'm not having any more children so I better just go ahead and do it (abdominal hysterectomy), so I did.

Theme 3: Social Supports Influenced Treatment Decisions

All of the women shared that they discussed the recommended treatment with their spouse or significant other, friends, and/or family members before deciding to undergo an abdominal hysterectomy. The influence of social supports was mentioned by 10 of the 14 women interviewed. For example, P1 mentioned, “I spoke to my husband and he said that he would support whatever decision I made.” P2 and P11 relied on their mothers and other family members for support in making a decision. P2 stated that she spoke to her mother and aunt about her doctor’s recommendation that she should try to have a child first and then undergo the abdominal hysterectomy. She stated,

> My mom was not too crazy about me having a child out of wedlock … my aunt on the other hand felt like I should just wait and see if the fibroids got any bigger because she said that sometimes they shrink on their own so I just decided to try

> to wait and see if they would shrink but I ended up having the hysterectomy.

P11 stated,

> When my doctor told me that I would need to have a hysterectomy, I was distraught. I drove to my Mom’s job and she came outside and spoke to me and calmed me down. She reassured me that based on how sick I’ve been and the amount of pain I was in constantly, this was probably best. I was scared and torn. My fiancé supported me through the whole ordeal. I had the hysterectomy and we got married after.

Likewise, P3 discussed having a child and the abdominal hysterectomy with her significant other before making a decision. She stated,

> I had a conversation with the guy that I was dating at the time. At that point, we had been together in a relationship for about 4 years, and everything was going good and we felt that we would be together for a while. The night before the hysterectomy, I even said to him like, are you sure you don't want to have children? Because if so, then I need to stop this and I need to look at other options. But when I go in there tomorrow morning, all bets are off. He was a little bit older than me and when I asked him the night before, he still did not really say that he wanted to have a child with me and he knew that this was my last chance to have a child. …I asked him and I guess I would have considered his response if he wanted to, but I would not say that he directly influenced my decision because I was still going to do whatever I decided I should do and what was best for me. I made the best decision for me and went ahead and had the

> hysterectomy and I have no regrets. Likewise, P5 stated that after talking to her doctor, she spoke to her daughter and “decided to move forward with the hysterectomy.

P7 had a conversation with her daughter who was knowledgeable about alternative treatments and the risks of delaying treatment. She stated,

> I consulted my daughter and she was like there are other ways of treating fibroids without removing the uterus, without hysterectomy like laser. So I spoke to my doctor and she said that I had to have the abdominal hysterectomy because of the number of fibroids and that it wasn’t wise to do laser in that case. My daughter told me not to delay making a decision as the fibroids will continue to grow bigger which is exactly what my doctor said. So, I did the hysterectomy.

Likewise, P10 relied on the advice of social supports and stated,

> One of my friends had fibroids so I talked to her but she didn’t have a hysterectomy, so I didn’t know much about a hysterectomy for fibroids. After talking to a few other friends, I found out that a bunch of my friends like 3 or 4 of them had fibroids too. One of my friends said that her doctor told her to have a hysterectomy but she said she wasn’t doing it because she wasn’t bleeding that bad and that she would wait it out. So I tried to wait, but the pain and bleeding were just too much for me. I was in so much pain that my parents told me to go ahead and do what was best for me and go on and live my life and that’s exactly what I did.”

Additionally, P12 reported,

> I discussed it with my sister and a friend who had a hysterectomy, but she had laser surgery to remove her fibroids. I assumed that I could not get laser that's why my doctor didn't mention it. My sister and my friend had an easy recovery and although I would have an abdominal incision instead of laser, I had a c-section with my babies so I knew about recovering from that so I was fine with it. …I moved forward after talking to my sister.

Noting that her spouse expressed support for her decision, P13 stated,

> You know, of course, I talked to my husband, but he was just supportive and allowed me to make the decision that I felt was best for me. My spouse and children deserve a better me and I deserve a better quality of life instead of having headaches and feeling weak.

P14 followed the advice of her social support instead of the recommendation of her doctor and stated,

> My cousin who had fibroids removed was more helpful to me than my doctor. She convinced me to try to bear the pain and bleeding and try to get pregnant. It was rough but so worth it when I managed to get pregnant. It was rough and my daughter was born prematurely because of the fibroids. In the end, everything was fine and it was worth it. I would do it again. Thank God for my cousin, her advice and support. She was right, I would have regretted not trying to have a child for the rest of my life. I was fine with doing the hysterectomy after my daughter was born …delaying the hysterectomy until I had a child was the right decision for me.

Theme 4: Severity of Symptoms Influenced Treatment Decisions

Many statements about the severity of symptoms influencing treatment decisions were mentioned by 12 of the 14 women interviewed. While some of the women initially rejected the treatment recommendation to try to conceive a child or delayed treatment to have more time to think, the severity of the symptoms (i.e., severe pain, heavy excessive bleeding, headaches, and anemia) ultimately influenced their decision to have the invasive abdominal hysterectomy.

The severity of symptoms led P1 to quickly decide to have an abdominal hysterectomy. She stated,

> I was in so much pain that I just went with whatever my doctor said let's do it. When I left her office in a matter of weeks, I had the surgery. I did not really have time to think, research, or anything. I had been through so much with the fibroids. In my mind, I was out of time.

A few women initially rejected treatment and kept trying until they conceived. Eventually, the severity of the symptoms led them to decide to have an abdominal hysterectomy. For example, P2 initially rejected the recommended treatment and tried to conceive. She had several miscarriages, and then, she finally was successful in having a baby. She later decided to have an abdominal hysterectomy due to continued severe symptoms. She stated,

> …my menstrual bleeding was more excessive. Sometimes I bled heavily for several weeks which caused me to become anemic. The bleeding got so heavy and so frequent that it was wreaking havoc on my life. I was having accidents with

> messing up my office chair and even in the conference room at work and it was quite bloody and embarrassing. I had already had my miracle baby by that time so I decided to call the doctor back and schedule the hysterectomy. After 2 miscarriages, I had already fought with the fibroids to get pregnant and carry my baby so I won. It was time to stop living in constant pain. So I just called my doctor and made an appointment to come in and talk about the hysterectomy.

Likewise, P5 reported, “I was like, just get these fibroid tumors out of me, because I was always hurting and in pain.” Similarly, P8 was experiencing severe pain and bleeding and also decided to have the hysterectomy.

Some women delayed treatment and endured symptoms until they successfully conceived. For example, P10 stated that she delayed treatment until she was successful in having a baby. Influenced by the severity of her symptoms, she later decided to have an abdominal hysterectomy. She stated,

> The pain was just unbearable. I was sick and had migraines all the time. My iron was low and I fainted a couple of times. I was bleeding and passing clots. I had several miscarriages because of the fibroids before I finally had my son. I was just glad that I fought through and held off having the hysterectomy until I was able to get pregnant. One child and I was done. I am glad to do the hysterectomy. I couldn’t take the pain anymore.

Likewise, P14 stated,

> After I had my baby I was glad to do the hysterectomy. I had messed up my clothes in public so many times over the years with the heavy bleeding that it was

> quite embarrassing. I had to sit on a dark towel in my car or on a trash bag and always had clean clothes, clean underwear, and maxi-pads in the trunk of my car. I was always in pain and dizzy from the bleeding. My iron was always low. It was really a mess. I was glad to be done with that.

A few women initially rejected treatment and tried to conceive but were unsuccessful. Eventually, the severity of symptoms led them to decide to have the abdominal hysterectomy. For example, P3 stated,

> During that 10-year period after being diagnosed, I just never got pregnant. I was having heavy, really, really heavy periods and back pain. Sometimes my period would last for 3 weeks and stop for a week and then start again. I was passing lots of blood clots and constantly messing up my clothes. I found out that the fibroids had grown very large, and they were causing complications. By then I was at a different point in my life and having a baby wasn't an important factor in my life at age 45, so I decided to have the hysterectomy.

Likewise, P4 indicated,

> We tried to see if I could get pregnant for about 11 months and finally, I returned to my gynecologist to discuss treatment because I was in so much pain constantly and sex became very painful as well. Eventually, I had to do something because the bleeding was quite a lot, like extreme, so I had the hysterectomy.

Other women initially decided to reject treatment and live with the severe symptoms for as long as possible. For example, P7 mentioned,

> I began to ask myself if I could deal with the nonstop bleeding and pain and the

> answer was no, I could not. So I had the surgery (hysterectomy). I was in so much pain and tired of living this way. I also wanted to avoid the fibroids getting even bigger and causing complications.

P9 stated,

> By the time I decided to get out of the military, the fibroids were out of control. I had fainted twice because of the bleeding and was living in constant pain. This was not the life that I worked so hard to enjoy. I remember that I went on a 14-day cruise and bled profusely the entire time and was in terrible pain. I could not even enjoy the cruise. So the decision was easy for me. When I got back from the cruise that I wasted money on, …I called my doctor to schedule the hysterectomy and I don’t regret it. It was best for me and that’s exactly what I did.

Likewise, P11 stated,

> I tried to wait and hold off on having the hysterectomy, but the pain and bleeding were just too much for me. It was just a bad situation all around. I was getting married and wondering how I was going to navigate heavy bleeding in my white wedding dress. When I went for the second fitting of my wedding dress, I was alarmed because all of a sudden it was too tight. My stomach all of a sudden looked like I was 6 months pregnant. I was just so tired of the bleeding and pain, it was just the worst. It was very difficult for me especially since I was so young and about to be a newlywed. I was in so much pain that my fiancé and parents told me to go ahead and do what was best for me and go on and live my life and that’s exactly what I did.

Additionally, P13 delayed treatment for over 12 years and had two children during that time. She stated,

> In 2022, my menstrual cycle began lasting for 25 days. I was bleeding heavily for 25 days straight and was constantly having headaches and feeling weak, and I said to myself that I am done with having this poor quality of life. So, I called the doctor and scheduled a consultation, and had the hysterectomy.

Theme 5: Family History Influenced Treatment Decisions

Two of the 14 women mentioned that their family history of reproductive cancers influenced them to quickly decide to have the recommended abdominal hysterectomy. For example, based on a family history of cancer, P6 assessed the risk and decided to move forward with the doctor’s treatment recommendation. P6 stated,

> …my Mom, her sister, my Aunt on my Dad’s side, and my cousin who is my age all died of cervical or ovarian cancer. I just wanted to get this behind me and the hysterectomy guaranteed that the fibroids would not return. On top of that, shortly after that my sister was diagnosed with fibroids and had to do a biopsy and they found suspicious cells like it could be cancer. My Mom died of cervical cancer so I just didn’t want to take any chances, so I had the hysterectomy immediately.

Likewise, P12 stated,

> I was also worried about cancer because that runs on my Mom’s side of the family. …I had family members who died of uterine and ovarian cancer... I was so afraid but at the same time, I already had 2 children so it was what it was although I really wanted to have maybe one more child, but I also was a divorced

> mother of two at the time. Anyway, I was glad to get it out of the way permanently. I was tired of the constant pain, bleeding, and living in fear that the fibroids could become cancer. I went ahead and did the abdominal hysterectomy and haven't had any problems since. I was glad to be done with it and not have to worry about cancer.

Theme 6: Emotional Stress About the Recommended Treatment and/or Overall Treatment Plan

Although all of the women who participated in this study decided to have the recommended abdominal hysterectomy, six out of the 14 women who were interviewed expressed that they became very stressed about the treatment recommendation and/or overall treatment plan provided by their doctor. The women expressed a range of emotions including feeling confused, stressed, rushed, scared, surprised, shattered, and devastated. For example, P2 who felt shocked, rushed, and uninformed, stated,

> …my doctor said that it was best for me to have a hysterectomy… He did say that I would not go into menopause because I will still have my ovaries. I was sitting there in shock because I was only 39 years old and did not have any children and he was sitting there telling me so matter of factly telling me this. … I felt like he was rushing me and I wasn't offered any choices or explanations about possible options even to simply explain why they were not good options for me. I felt myself like shatter into a million pieces inside. It's like I just went on autopilot to keep from having a nervous breakdown. I couldn't even think.

Likewise, a devastated P6 also felt rushed and stated that,

> “When my doctor said the word hysterectomy, I was devastated. It was just too much for me, I was in denial. I was so scared so the decision was hard. ....I did not like how she was rushing or kind of pressuring me to make a decision saying let’s handle this so that I can start feeling better. It felt cold and impersonal to me and the decision that will result in me not being able to have a child is a lot deeper than just feeling better the day after surgery. At least it is to me because the emotional pain is forever. At one point I said to her that as a woman I expected her to have a better understanding of how difficult the decision is. She apologized to me so at least I got that from her that day.

P8 stated that she was surprised and confused by the treatment recommendation made by her doctor. She also stated that,

> I was very surprised when she (the doctor) said that I needed to have a hysterectomy. The thing that was most upsetting to me is that every year, I was going to her and she was monitoring the situation so I was so confused. I just don’t understand how we moved from one extreme to the next so quickly. She should have known that the fibroids we getting bigger. How did she not know?

Similarly, P10 stated,

I was very stressed out and worried because the doctor kept saying that I should have a hysterectomy because I would not be able to carry a child in my condition with the fibroids. My husband and I decided that God has the final say and we continued to try to get pregnant again. I tried to hold fast to my faith in God and prayer whenever the waves of doubt came crashing in. It was stressful and there were days filled with disappointment but my faith in God prevailed. …I had two miscarriages… I am glad we took the chance and did not listen to the doctors because our son is healthy and strong today.

P11 shared that she was distraught about the treatment recommendation and stated,

> "First of all, like I said I was very upset, distraught and my doctor just didn't spend much time with me or giving me information or comforting me. …She just said I need to have surgery (an abdominal hysterectomy) and that I should try to get pregnant soon and then she kind of rushed to the next patient's room and left me with her assistant PA. Mentally, I was drained. I sat in the parking lot and cried for hours. My fiancé and Mom were calling me repeatedly but I was too distraught to answer my phone. Eventually, I spoke to my Mom and everything, and she told me to come to her job. She came outside and spoke to me and calmed me down.

P14 stated, "It was earth-shattering to me when my doctor said I needed to have a hysterectomy because a hysterectomy is so final, especially for a woman who does not have children. I didn't have children at the time. I was devastated but thank God my cousin had gone through fibroid treatment before so she advised me on what to do."

Theme 7: Lack of Knowledge About Postsurgical Effects

Five of the 14 women shared that their bodies changed after the abdominal hysterectomy. Some women expressed that they were unaware and were not told that they would experience postsurgical effects such as weight gain, hot flashes and brain fog. A few of the women shared that they were unaware that their hysterectomy included the removal of their ovaries which would cause their body to go into menopause. The women also expressed that they were unaware that they would be prescribed hormone medication or would have to undergo hormone replacement therapy following the abdominal hysterectomy that included the removal of their ovaries. For example, P2 stated that she was unaware of the postsurgical effects. She stated,

> I second guess the decision often especially as I get older. My body immediately changed after surgery and I gained a whole bunch of weight and continue to struggle with my weight to this day. I have never weighed more than 138lbs in my entire life. I went from weighing 138 to 180 lbs. in the matter of 3 or 4 months after the hysterectomy and have been fighting to stay under 200 lbs. ever since. I read that a lot of women who had hysterectomies have complained about the weight gain and belly fat.

While P5 was aware that the abdominal hysterectomy would trigger menopause, she shared that she was unaware of other postsurgical effects. She stated,

> the hysterectomy triggered menopause immediately so the hot flashes and the brain fog that come with menopause was difficult. I have spoken to my doctor and she tried to minimize my concerns as if they are totally unrelated to the hysterectomy. It is as if doctors do not want to discuss it and want you to believe that you should just spend the rest of your life like this and that's normal. They say things like that happen to every woman when she is in menopause like you are just 98upposee to live with it. It is almost like you are invisible and no longer matter. I know my gynecologist is wrong about my symptoms not having to do with the hysterectomy because I know of other women who have the same

> symptoms including depression since their hysterectomy.

Likewise, P8 stated was aware that her body would go into menopause following the abdominal hysterectomy. However, she shared that her doctor never discussed placing her on hormone replacement therapy. She stated that,

> a lot of things happened after the hysterectomy like I was placed on HRT hormone replacement and had breast cancer twice. I didn't know that I would have to do HRT. I know that the doctors are not gonna admit it but I believe that there is a causal relationship between the HRT and my two occurrences of breast cancer within a 5-year period after the hysterectomy. No one in my family ever had breast cancer. She admitted to some mistakes like not monitoring, saying that the fibroids would shrink and then they got bigger each year while she was monitoring them regularly and she did not realize that they were growing. Those mistakes cost me my health.

A few women shared that they were unaware that their abdominal hysterectomy included the removal of their ovaries and would trigger postsurgical effects such as menopause. For example, P1 stated,

> …with having the hysterectomy, I went into menopause right away and I didn't even understand what was happening to my body. No one had discussed menopause and what that meant. No one explained how the loss of hormones would affect me. All of a sudden, I was emotional and crying for no reason. I was feeling depressed and then I had a wound problem that opened up and was infected. I had to get the hysterectomy incision packed and drained for a couple

> months, my hair fell out and the shape of my body changed. It was horrible and no one had prepared me for any of this. I was young and knew nothing about menopause brought on by the hysterectomy. My whole life changed.

Likewise, P12 stated,

> I certainly did not even know at the time that there were different types of hysterectomies and he (the doctor) did not discuss what type he would perform. Imagine my surprise when after surgery, one of my prescriptions was for hormones. I was so confused and the nurse explained that I no longer had my ovaries and my body would be going into menopause. I never cried so much in my life. So, there I was unknowingly plunged into menopause at age 40 with no discussion or consideration about how it would affect my life. And another thing…after the surgery, it was as if I was a totally different person. I had always been a slender person about 117 lbs. Within 6 months of the surgery, I blew up to 167 lbs. and became depressed. People would see me and not even recognize me, that's how much my body changed. I kept complaining to my doctor and she said that it is unrelated to the hysterectomy, but I know that it is related. Also, sex became extremely painful after the hysterectomy. I told my doctor at the time and she said well that's because my cervix was removed along with my uterus during the hysterectomy. How was I ever supposed to know that? You would think that all of this would have been discussed before so that I would know what to expect.

Theme 8: Postsurgical Psychosocial Impact was the Hardest Part of Treatment

Postsurgical psychosocial factors were mentioned by six of the 14 women interviewed. The women expressed that they are still dealing with the psychosocial impact and it is the hardest part of their treatment. A variety of psychosocial impacts including disappointment, unfairness, hurt, sadness and doubt were mentioned by the 6 women. For example,

P2 indicated the difficult part of her decision. She shared,

> It hurts to know that I will never be able to have my own children. It’s like all of this devastation to my body and soul and nothing to show for it. All I can do is try each day to move forward and enjoy life and not dwell on the past. For the most part, I have done that pretty well, but still, some days are hard.

P6 stated,

> It is disappointing but I am still hurt deep down inside feeling like I didn’t ever stand a chance of being a mother. Apparently, it just was never a part of my destiny. There is always some hurt there for sure, but my life is fine. You know, sometimes life can be so unfair.

Likewise, P8 stated,

> The hardest part is that I have been through a lot with the whole ordeal, and after the hysterectomy and all of that, it makes me wonder if I should have ever trusted my doctor. I wonder about that sometimes.

According to P11, the most difficult part of treatment was:

> Not being able to have a child with my husband. I know he would have loved to

> have a son even if it were a girl. He would make a great Dad. I mean no woman ever thinks that she would not be able to have children or that the choice would be taken from her. You as a woman want to have biological children. It’s such a tough decision to have to make when you are in pain and suffering. Every woman would like the ability to choose, and I feel like my choice was taken from me, it’s unfair, almost like being robbed. Actually, we were robbed.

Similarly, P12 stated,

> I have struggled with depression ever since deciding to have the hysterectomy and have a therapist that I see regularly. It is just a very haunting decision and a lot to deal with. I am doing much better right now.

P14 stated,

> While my situation ended well for me because I fought through the pain and complications to have a child, it was a gut-wrenching process. I often find myself second-guessing if I gave up too easily or should have endured longer and tried to have another baby. Yes, I am grateful for my miracle child, but there are always lingering doubts about whether or not I made the right decision to have the hysterectomy after she was born. I personally feel like women going through making such a tough decision could benefit from some counseling. I can’t imagine what it must be like for those who do not have children, they just were not as lucky as me. They must be devastated and I am devastated for them because that was almost me, almost, but God had a different plan. I try to focus on that and when the doubt rolls in, I push it out and fix my mind on being grateful.

Summary

The purpose of this qualitative study was to explore the lived experiences of Black women who decided to have an invasive abdominal hysterectomy for benign fibroids. I sought to address the following research question: What are the lived experiences of Black women who decided to undergo the procedure of abdominal hysterectomy for benign fibroids? The findings showed doctors recommended an invasive abdominal hysterectomy as the only treatment option and some of the women were unaware of alternatives. Many of the women experienced great emotional stress and felt rushed to make such a personal, sensitive decision that would result in the end of their ability to become pregnant. Some women, especially those who did not have children decided to delay their treatment decisions for a variety of reasons, including not being able to emotionally deal with the sensitive, personal decision that would culminate in ending their ability to have children, or they delayed their treatment decision to try to have a child before proceeding with the abdominal hysterectomy.

The findings also revealed that for some women, a family history of cancer and reproductive health issues, as well as severe symptoms and complications influenced them to decide to undergo a hysterectomy. Most of the women also were influenced by the unrelenting symptoms they were experiencing such as severe pain, heavy excessive bleeding, headaches, anemia, etc. Almost all of the women discussed the recommended treatment of a hysterectomy with their social supports (i.e., spouse or significant other, family members, and friends) before making a decision. Some of the women lacked knowledge about the postsurgical effects of an invasive abdominal hysterectomy and felt that was the hardest part of treatment. A few women stated that menopause and hormone treatment had never been discussed. Lastly, some women felt that the psychosocial impact is the hardest part of treatment. Many of the women experienced lingering doubt about whether the abdominal hysterectomy was the right choice, uncertainty about trusting their doctor and wondering whether their doctor really recommended what was best for them, sadness and regret about not receiving adequate information or educating themselves about their options, and a few women stated that the post-operative ramifications coupled with overall doubt are the hardest part of the treatment. In Chapter 5, I will reiterate the purpose of the study, provide a detailed interpretation of the findings in the context of the SEM and HBM theoretical frameworks, describe recommendations for further research within the boundaries of this study, provide implications for social change, and a conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative phenomenological study was to explore the lived experiences of Black women who decided to undergo an invasive abdominal hysterectomy for benign fibroids. Researchers do not know why Black women are more likely to decide to undergo the invasive treatment of abdominal hysterectomy for benign fibroids (Price et al., 2017; Sengoba et al., 2017). As discussed in Chapters 1 and 2, although this reproductive health disparity costs the U.S. government health care system billions of dollars each year, fibroid research and fibroid treatment remains one of the bottom 50 health conditions receiving very little federal funding for research (see Society of Women's Health Research, 2020). The lived experiences of Black women regarding what influenced their decision to have the invasive treatment of an abdominal hysterectomy for benign fibroids remain underexplored in research (Alexander et al., 2019).

I addressed the gap in the literature identified in Chapter 1 by exploring the influences, choices, and decisions of Black women who had an abdominal hysterectomy. This chapter contains an analysis and interpretation of the findings in the context of the SEM and HBM theoretical framework within the scope of the study. The chapter also includes a summary of the key findings to provide a further understanding of Black women's lived experiences with invasive abdominal hysterectomy for benign fibroids, recommendations for further studies, a description of the study's potential implications for positive social change, and a conclusion with a discussion of the key essence of this study.

Interpretation of the Findings

In this section, I interpret the findings that I presented in Chapter 4. I confirm, disconfirm, or extend the knowledge in the discipline by comparing the findings of the current study to what has been found in the peer-reviewed literature described in Chapter 2. The findings will be presented by the three categories that emerged, and the discussion will encompass eight themes.

Category 1: Factors Contributing to Treatment Decision

Theme 1: Invasive Abdominal Hysterectomy was the Only Treatment Recommended

As discussed in Chapter 2, although the advantages of minimally invasive treatments for benign fibroids have been well documented, Black women are 3 to 4 times more likely to receive a treatment recommendation of an invasive abdominal hysterectomy than women of any other race. ACOG, the primary professional organization for licensed, board-certified obstetrician-gynecologists (ob-gyns), has recommended minimally invasive approaches for the treatment of benign fibroids. Despite ACOG best practices, as discussed in Chapter 4, the 14 Black women who participated in this study received the treatment recommendation of an invasive abdominal hysterectomy for benign fibroids as their only treatment option. The findings of this study confirm the findings of numerous key studies showing that Black women are more likely to receive the treatment recommendation of and undergo an invasive abdominal hysterectomy for benign fibroids (McClurg et al., 2020). As discussed in

Chapter 2, a study of health records within a large health system found that even when the same symptoms were present, Black women still received the most invasive treatment of an invasive abdominal hysterectomy at a much higher rate (Katon et al., 2019). This study confirmed another notable study of prevalence trends and determinants of health in the United States using BRFSS data for 2006 through 2016. The findings of this study are consistent with previous research showing that Black women are more likely to receive the treatment recommendation of invasive abdominal hysterectomy and are more likely not to be aware of other treatment options.

ACOG fibroid management best practices include clear, detailed, ongoing shared patient-physician communication and decision-making about fibroid treatment options and factors that influence each treatment route including the benefits, risks, and effects (ACOG, 2017). ACOG's best practices clearly state that every ob-gyn should also discuss and consider each woman's preferences and values (ACOG, 2021). Most of the women in this study were diagnosed with benign fibroids. and the progression of their disease was monitored by their doctor for at least a period of 6 months or more before deciding to undergo an invasive abdominal hysterectomy.

As discussed in Subtheme 1-1 in Chapter 4, nine of the 14 women who participated in this study stated they were unaware of alternative treatments and their doctor did not discuss or educate them about alternative treatments or why they were not a good fit. Despite the best practices cited by ACOG (2021), most of the women in this study stated they did not engage in any discussions with their doctor about treatment options and treatment routes. Many of the women expressed feelings of surprise about their doctor's recommendation of an invasive abdominal hysterectomy and felt there was a lack of communication and shared decision-making that could have taken place during the monitoring period. Some of the women stated that they were confused as to why the progression of the disease was being monitored over the years only to end with the recommendation of an invasive abdominal hysterectomy ending their ability to have children. Although the monitoring of fibroids and the progression of the disease is a best practice within the obstetrics-gynecology community, according to ACOG (2022), the monitoring period should be used to periodically reexamine, reassess, and discuss the situation and available treatment options.

Research shows that recall bias may be a potential factor and that a patient's perception of their condition may be difficult to accept (VanNoy et al., 2021). However, nine of the women stated that their doctor did not engage them in a discussion about treatment options and that they were unaware of alternatives at the time they decided to undergo the invasive abdominal hysterectomy for benign fibroids. Findings from this study confirm a significant number of peer-reviewed studies in Chapter 2 showing that not only are Black women more likely to receive the treatment recommendation of invasive abdominal hysterectomy, but Black women are also more likely not to be aware of other treatment options (Pollack et al., 2020). These statements raise ethical questions and possibly implicate possible treatment biases.

As discussed in Subtheme 1-2, the remaining five women who participated in the study said they were aware of alternative treatments and that their doctor provided information and discussed the alternatives, but ultimately the shared decision was made that the invasive abdominal hysterectomy was the best-fit treatment of various reasons. All 14 women stated that at diagnosis or upon treatment recommendation, their doctors mentioned that they should try to conceive if having children was a part of their fertility goals. However, no education or information about fertility planning was provided.

The findings of this study can further extend the knowledge in the discipline as statements by most of the women indicated the desire for more information and discussion about treatment options including detailed explanations of why each treatment option was or was not a good fit. Many of the women stated that they felt they had no voice and were told their treatment recommendation rather than engaging in a discussion about options. Analysis of participants' lived experiences also showed that they desired more empathy and time to process the treatment information given rather than feeling pressure to schedule their surgery. The findings of this study can further extend the knowledge in the discipline as most of the peer-reviewed studies have heavily addressed the medical side of fibroid treatment with limited mention of the need to educate patients so they are fully aware of all treatment options long before having to make a treatment decision that may not align with their fertility goals.

Category 2: Influences on the Choice to Have an Invasive Abdominal Hysterectomy

Theme 2: Women’s Desire to Have Children Influenced Their Treatment Decisions

Consistent with the findings of Scott (2020) and Yu et al. (2018), in this study, some of the women reported delaying talking to their doctors about the severity of symptoms and further delayed their treatment decisions. As discussed in the literature review, Pollack et al. (2020) and VanNoy et al. (2021) found on average, Black women wait up to 4 years longer than White women before seeking treatment. Black women who delayed treatment were asked the reason for their decision to delay, and they cited the ability to have the choice to have children as a driving factor for the delaying treatment. On average, the women in the study had an invasive abdominal hysterectomy 6.7 years after being diagnosed with benign fibroids for various reasons. For some women, the progression of the disease was being monitored by their ob-gyn during that time, and delaying treatment was a part of their treatment plan.

Other women in this study stated they pushed thoughts of having a hysterectomy to the back of their minds and endured, some for more than a decade, while others made the decision quickly. When P13 who had fibroids gave birth to a son and then a few years later, a daughter in 2012, her gynecologist once again mentioned the treatment of hysterectomy. P13 told her doctor the fibroids were not bothering her while she continued to endure the escalating symptoms because it was important to her to have the choice to preserve her fertility. She felt since she successfully conceived and gave birth to two children despite the prior recommendation of a hysterectomy, she would continue to choose to preserve her fertility by enduring the severe symptoms until almost a decade later when severe symptoms influenced her to have the abdominal hysterectomy. It should be noted that had she not chosen to endure the severity of the symptoms for well over a decade and had the hysterectomy as recommended by her doctor, she would not have had the two children she gave birth to during that time. Several other participants in the current study minimized the severity of their symptoms when asked by their doctors. Similarly, an analysis of participant statements in the present study confirmed the findings of studies presented in the literature review (i.e., Riggan et al., 2021; Sanei-Moghaddam et al., 2018) confirming that Black women often do not share the severity of their symptoms with their doctors to preserve their fertility choices by not reporting severe symptoms.

Many key studies have found that delaying treatment negatively impacts treatment options (Al-Hendy et al., 2021; Scott, 2020). I can neither confirm nor disconfirm those findings without more information about the women’s treatment plan and why each woman’s doctor only recommended an invasive abdominal hysterectomy as the only treatment option. While some of the women in this study who desired to have children or were actively trying to have a child chose to delay treatment to preserve the choice to have children, the only treatment option recommended by their doctor was to have an invasive abdominal hysterectomy. Confirming or disconfirming the extent to which the women in this study impacted their treatment choice by delaying treatment is beyond the scope of this study. Results from this study confirmed significant findings of key studies (i.e., Riggan et al., 2021; VanNoy et al., 2021) that indicated that more communication is needed between doctors and patients. Doctors need to discuss and plan future individualized obstetrical outcomes for women who desire fertility, discuss the quality of life, and better align patient education, treatment approaches, and patient goals.

Theme 3: Social Supports Influenced Treatment Decisions

Previous research concluded that 80% of patients’ choices were guided by their social supports rather than by their interactions with their physicians (VanNoy et al., 2021). The current study confirms those findings. Most of the women in the present study indicated they discussed the recommended treatment of invasive abdominal hysterectomy with their social supports (i.e., spouse or significant other, friends, and/or family members) before deciding to undergo the recommended treatment. Likewise, confirming the findings of Pollack et al. (2020), the participants were encouraged by their social supports to carefully consider their fertility goals before making a decision even if their fertility goals were outside of the recommendation by their doctor.

Women in this study who did not yet have children were encouraged by their social supports to delay treatment and try to get pregnant. Additionally, findings show that women in this study who had at least two children were encouraged by their social supports to focus on the quality of their life and do what was best for them or to have an abdominal hysterectomy if they did not plan to have more children. These lived experiences involving social supports confirm the findings of numerous studies that indicate that Black women tend to discuss their fibroid diagnosis with a small circle of social supports more so than with their doctor (Chen et al, 2018; Sengoba et al., 2017).

Many of the women in this study mentioned they were confused or upset about their treatment recommendation or the lack of patient education yet many of the women did not question their doctor and chose to follow the advice of their social supports. Despite the underpinnings of influence by their social supports, in sharing their lived experiences, the women in the present study were adamant that their social supports did not influence their decisions but stated they did consider the opinions of their social support. However, findings show that some of the women followed the advice of their social supports even when it differed from that of their doctor (see VanNoy et al., 2021).

Their social support offered empathy and some had lived experiences with fibroids or hysterectomy that could not be offered by their doctor. The findings of this study show that the women relied on information and support from their social supports as they considered the recommended treatment option. Similarly to the findings of Pollack et al. (2020) and Riggan et al. (2021), as discussed in Chapter 2, the women in the present study found the advice of their social supports to be integral in processing their feelings, priorities, and choices in making their treatment decisions.

Theme 4: Severity of Symptoms Influenced Treatment Decisions

As discussed in Chapter 2, findings from numerous studies showed that Black women tend to have more numerous and larger fibroids than women of any other race (Giuliani et al., 2020; Gray et al., 2020). Further complicating treatment decisions are findings of research showing that Black women often delayed treatment and often made their treatment decisions based on the severity of their symptoms (Alexander et al., 2019; Aninye & Laitner, 2021; Bonafede et al., 2018). As presented in the literature review in Chapter 2, findings of studies show that Black women suffer more fibroid-related symptoms such as excessive bleeding, severe anemia, low blood cell count, chronic fatigue, and back and abdominal pain than women of any other race (Pollack et al., 2020; Wang et al., 2022; Yu et al., 2018).

Key findings from the present study confirm previous research. For 12 of the 14 participants, the severity of their symptoms and their poor quality of life triggered them to finally act in deciding to have the recommended invasive abdominal hysterectomy. Many of the participants in this study described their quality of life as “poor, having headaches, excessive bleeding, severe anemia, chronic fatigue, and back and abdominal pain and messing up their clothes, bed sheets, and car seats with heavy bleeding. The women also described incidents where they often felt embarrassed in public (i.e., at work, church, out on a date, at a restaurant, or movie theatre) when heavy bleeding soaked through their clothes and was seen by others on their clothes and chairs. The statements align with statements made by women in previous fibroid research studies. The findings of this research study confirmed the findings of numerous research studies showing that Black women suffer more severe fibroid symptoms than women of any other race, endure severe symptoms for longer periods and often make their treatment decision based on the severity of their symptoms (Murji, 2020; Schlaff et al., 2020; Senogoba et al., 2017; Soliman et al., 2017).

Theme 5: Family History Influenced Treatment Decisions

As discussed in Chapter 4, two of the 14 women indicated that their cue to act quickly in deciding to have the recommended invasive abdominal hysterectomy was triggered by their family history of cancer of cervical or ovarian cancer. One woman stated that her mother had fibroids and died of cervical cancer and a few other family members also died of cervical and ovarian cancer. The other woman’s family members had a history of cancer, and her sister was diagnosed with fibroids around the same time as her diagnosis but was referred for a biopsy due to suspicious or abnormal cells. Both participants immediately decided to have the recommended abdominal hysterectomy because of their family history of cancer. As discussed in Chapter 2, findings of a systematic review of fibroid studies across the U.S. showed that Black women often considered their family's risk of cancer when making fibroid treatment decisions (Al-Hendy et al., 2017). The findings from the current study confirmed previous research findings indicating Black women with fibroids and a family history of cancer often quickly assessed their risk and make a decision to have an invasive abdominal hysterectomy based on their family history of reproductive and other cancers (Aninye & Laitner, 2021; Zota & VanNoy, 2021).

Category 3: Presurgical and Postsurgical Impacts

Theme 6: Emotional Stress about the Recommended Treatment and/or Overall Treatment Plan

Although subjective and relatively new in concept, the role of emotions is important to qualitative research (Schwab & Margaritis, 2020). As supported by the results presented in Chapter 4, some of the women expressed presurgical emotional stress about their recommended treatment and/or the overall treatment plan, which would result in the permanent loss of fertility. Consistent with the literature discussed in Chapter 2 (i.e., Bonafede, 2018; Emerson et al., 2019; Lawson, 2017), most of the women who participated in this study expressed emotional stress upon receiving news of the recommended treatment from their doctor. These emotional responses confirmed that although most of them were previously diagnosed with fibroids, and continued to experience pain, heavy bleeding, and other lifestyle impacts, the women did not perceive the risk of having to prematurely end their fertility choices. While some of the women stated that having a biological child was not an essential goal in their life, they still wanted the ability to make a choice.

When asked during the interviews, all the women stated they trusted their doctor as a medical expert. However, similarly to the findings of Bonafede et al. (2018), some of the participants stated that upon treatment recommendation, they felt confused about their doctor’s sudden change in management advice from monitoring to recommending a hysterectomy, which would end their ability to have children. While the results of this study disconfirmed the findings of studies such as Scott (2020) about widespread community norms of mistrust of the medical sector in the Black community, the findings of this study show the need for increased patient–doctor communication. As discussed by ACOG (2021), best practices in OG-GYN care recommend that doctors anticipate and initiate conversations with women earlier to discuss their reproductive health and fertility goals to ensure the women are properly educated about their diagnosis, treatment plan, and treatment recommendations. The ongoing conversations must include justification and discussion about why each treatment option may or may not be the best-fit treatment to avoid overwhelming women with important information and discussion for the first time at a treatment decision.

Theme 7: Lack of Knowledge About Postsurgical Effects

While a few of the women in the current study stated they have not experienced any postsurgical complications, some of the women in the current study experienced unexpected postsurgical effects. Their experiences mirror the findings of previous research studies by Aninye et al. (2021) and Alexander et al. (2019), showing that most women who had an invasive abdominal hysterectomy felt they were not well-informed about what to expect post-surgically. According to the research, most women are confused about the type of invasive abdominal hysterectomy they received. In Chapter 4, P1 and P8 stated that they were unaware that their hysterectomy included the removal of their ovaries which triggered the onset of menopause. P12 was unaware that she would need to begin hormone replacement therapy and shared that her doctor stated the hormone replacement therapy was necessary “to help balance her emotions and hormones before she killed someone.” Similarly to the findings of the studies in the literature review (i.e., Aninye et al., 2021; Alexander et al., 2019) and findings of the current study revealed that a few of the women did not have knowledge about the type of invasive abdominal hysterectomy performed and did not expect to begin menopause after their hysterectomy. As confirmed in the findings of Leyland et al. (2022), most of the women in the current study stated they lacked knowledge about menopause, hormones, and other postsurgical effects.

Some participants recalled having a discussion with their doctor about the recovery process but felt insufficiently informed while others were adamant about not receiving any information. Statements made by women in this study about the lack of patient education and treatment risks, benefits, and effects confirmed the findings of many previous key studies. These findings may have ethical considerations as medical ethics require doctors to disclose all information necessary (i.e., treatment recommendations, alternatives/options, risks, benefits, and consequences of delaying or refusing treatment) so that patients can make prudent, informed decisions. The findings of this study confirmed the research findings of key studies (i.e., Sengoba et al., 2017; Vodovotz et al., 2020; Zota et al., 2021), affirming that women want shared-decision making with their doctors and even if their choice is not to have children, women want to retain the choice to preserve their fertility whenever possible.

Theme 8: Postsurgical Psychosocial Impact was the Hardest Part of Treatment

Most key studies on the phenomenon do not capture the psychosocial impact on the women who had an invasive abdominal hysterectomy for benign fibroids. As discussed by VanNoy et al. (2021), most hysterectomy studies are flawed in design because of the inconsistent timing of the presurgical and postsurgical assessments coupled with the lengthy healing process associated with an invasive abdominal hysterectomy. As discussed by Callegari et al. (2019), the individual psychosocial impacts experienced by each woman are further complicated by their own prior psychosocial experiences, postsurgical experiences congruent with their surgical procedure such as the removal of the ovaries triggering menopause, and the body's differing natural healing process. Psychosocial impacts can also be affected by the external environment (i.e., being surrounded by loved ones who are positive and supportive of the recovery process).

A hysterectomy can be a difficult procedure for a woman and has physical and emotional consequences. Research shows that postsurgical care tends to only focus on medical milestones and impacts (VanNoy et al., 2021). The health of the whole woman is rarely considered in the presurgical and postsurgical recovery process. As discussed by Riggan et al. (2021), these factors alone cause psychosocial impacts to be the hardest part of treatment. Some of the women in the current study confirm the findings of VanNoy et al. (2021) and Riggan et al. (2021), reporting that they experienced confusion about postsurgical changes in their bodies (i.e., weight gain, unexplained emotional outbursts, not feeling like themselves, sadness, and depression). Later, they began to doubt they made the right decision to have the abdominal hysterectomy and began feeling mistrust of their doctor. It should be noted the women in this study who experienced the most difficulty with the psychosocial impacts of doubt and postsurgical mistrust of their doctor were women who did not have children at the time of their abdominal hysterectomy and or women who developed postsurgical complications that required further surgeries and care.

Contextual Application of the Social Ecological and Health Belief Models

Although Black women are the population disparately affected by the treatment of invasive abdominal hysterectomy for benign fibroids, the voices of Black women sharing their lived experience and providing insight on what influenced their treatment decision is barely present in the research (Lawson, 2017). The SEM and HBM were used to further explore the influences, choices, and decisions of Black women to learn what triggered them to decide to undergo an abdominal hysterectomy for benign fibroids.

This study applied the interconnectedness of the SEM and the HBM. Not many studies exist with the application of a theoretical framework in fibroid or fibroid treatment management. The use of the SEM and HBM theoretical frameworks provided insight to better understand the influences on the treatment decisions made by Black women and provided context that is currently rarely found in the research (Riggan et al., 2021). Additionally, the application of the theoretical frameworks provided theoretical implications for a better understanding of what influenced the women’s decisions and cued them to act by deciding to have the most invasive procedure as treatment for benign fibroid.

Social Ecological Model Contextual Findings

As discussed by Riggan et al. (2021), Black women are 3 to 4 times more likely than women of any other race to undergo an abdominal hysterectomy instead of a less invasive and less damaging laparoscopic or robotic procedure for benign fibroids. Within the context of the phenomenon at the macrosystem level of the SEM, the findings of this study were similar to the previous research findings showing that the women in this study also lacked knowledge about treatment options and postsurgical effects and heavily relied on the advice of their social supports. Research findings of Marsh et al. (2018) and Zaritsky et al. (2019) showed that the sensitive, complex lived experiences of Black women who decided to have an invasive abdominal hysterectomy for benign fibroids are historically heavily influenced by beliefs, traditions, and social supports.

Through the microsystem level of the SEM, a deeper understanding of the level of influence that social support held for many of the women was revealed. Not only were many of the women in the study lacking in knowledge pre and postsurgery, but instead of questioning their gynecologist or expressing disagreement, they relied on their social supports for guidance in making decisions. As discussed by VanNoy et al. (2021), 80% of patients' choices were guided by their social supports rather than by their physicians. Through the lens of the microsystem level of the SEM, previous research findings were confirmed by this study. As discussed by Sengoba et al. (2017), and confirmed by this study, Black women often readily accepted guidance from social support even when it differed from the recommendations of their doctor and never discussed the matter with their doctor to provide an update or discuss changes in options or new developments.

As explained in the literature, a woman's sensitive personal decision to end her ability to have children has differing psychosocial impacts for every woman (Riggan et al, 2021). The chronosystem sphere of the SEM, which encompasses an individual's overall experiences is greatly impacted by such a difficult decision. Application of the SEM took into account key themes that revealed commonalities in each woman's experience from lack of knowledge about treatment options, the desire to have the choice to have children, the trust they had for their doctors despite feeling confused at times, lacking postsurgical knowledge and leaning on their social support for guidance in making the life-changing decision that will end their ability to have children. As supported by findings from Bogardus et al. (2019) and VanNoy et al. (2021), all of these variables over time can create major complex psychosocial experiences within the chronosystem sphere. These major events have lasting impacts and can affect the decision-making process. These occurrences are also a part of each woman's chronosystem of events experienced over time leading up to a major life-changing decision. Similarly to the findings of VanNoy et al. (2021), many of the women in this study are still experiencing long-term, varying psychosocial impacts such as doubt, regret, postsurgical feelings of mistrust about their doctor's treatment recommendation, and confusion about postsurgical effects. As discussed in the research and confirmed by this study, these complex psychosocial impacts are the hardest part of the treatment, they remain a part of the chronosystem, and these impacts may surface at any time.

Health Belief Model Contextual Findings

The constructs of HBM applied in this study were perceived severity, perceived benefits, and cues to action. Application of these three constructs of the HBM provided insight and confirmed previous research on the decision-making behavior that ultimately led the women to decide to have an invasive abdominal hysterectomy for benign fibroids. Through the lens of the HBM, exploration of the influences on treatment decisions made by Black women with benign fibroids provides context that is currently rarely found in the research (Riggan et al., 2021). As shown in Table 1, most of the women in this study were diagnosed with benign fibroids for at least 6 months before receiving treatment recommendations from their doctor. Despite their symptoms, half of the women reported being surprised or shocked by their doctor's recommendation of an invasive abdominal hysterectomy for their benign fibroids.

As discussed by Riggan et al. (2021), women with fibroids can have a different perception of the severity of the illness because they have had a poor quality of life for so long as they navigated the heavy bleeding, anemia, headaches, stomach and back pain, and other daily symptoms that are a part of living with benign fibroids. Findings of key studies (i.e., Marsh et al., 2020; Murji et al., 2020) show that Black women suffer more severe symptoms and are less likely to report the severity of their symptoms to their doctor especially if their goal is to preserve their ability to have children or delay decision-making. Statements by the women in this study confirmed that they perceived the severity of their symptoms differently than their doctor in an attempt to preserve their ability to have children and often, to delay making a difficult treatment decision. As discussed in the findings of Murji et al. (2020) and confirmed by this study, the women perceived they would be given some type of treatment plan that would preserve their ability to have children. Their perception of the severity of their illness did not align with that of their doctor.

It is vital to explore Black women's influences and decision-making behavior because Black women represent 55% of invasive abdominal hysterectomies for benign fibroids compared to 22% of White women (Zaritsky et al., 2019). As previously discussed in the findings of Herrmann et al. (2018) and Marsh et al. (2020), Black women often made their treatment decisions based on the sensitive emotional experiences of watching loved ones suffer or die from cancer, or often base their decisions on the lived experiences of their social supports rather than discussing or questioning their doctor. Similarly, in this study, I found that some of the women readily accepted and made decisions based on perceptions about genetics, family history, and guidance from their social supports, and although they had questions, they did not question their doctor or request further education to learn of options or details about postsurgical effects.

Similar to the findings of Herrmann et al. (2018) and Schloemer et al. (2018), once the women in this study were given a treatment recommended by their doctor, most of them engaged in discussions with their social supports and gave thought about whether or not they could continue to endure the severity of the symptoms. A few of the women who had a family history of reproductive cancer quickly decided that a family history of reproductive diseases and cancer was their cue to act and quickly decided to have an abdominal hysterectomy. In the application of the HBM, the 14 women in this study ultimately weighed the perceived severity and perceived benefits but most of them ultimately were cued to act based on the severity of their symptoms and/or a family history of reproductive and other cancers. The interconnectivity of the SEM and HBM to the major findings confirms previous research and provided a deeper understanding of what influenced the women and what ultimately triggered them to act in deciding to have the most invasive procedure as treatment for benign fibroids (see Cramer & Kapusta, 2017; Lawson, 2017). These findings reveal implications for more targeted fibroid treatment awareness and education programs specifically designed for Black women and the need to focus on the implementation of patient-doctor shared treatment planning and decision-making in fibroid management.

Limitations of the Study

As discussed in Chapter 1, the anticipated limitations were confirmed during this study. The findings of this study are considerable within the context of the qualitative phenomenological study design. As anticipated, the generalizability of the study results may not represent the lived experiences of all Black women who have experienced the phenomenon. The findings of this study highlighted the detailed, rich lived experiences of 14 Black women who decided to undergo a hysterectomy for benign fibroids. A limitation of confirmability of the data exists due to the nature of the study design. The women’s lived experiences are confidential and taken at their word. Any attempt to verify their lived experiences would be in direct violation of the confidentiality agreement. Additionally, the transferability of this study is also limited by sex and race and is only transferable and limited to Black women since they are the population most disproportionately treated with invasive abdominal hysterectomy for benign fibroids. It must also be noted that a limitation to this study may exist as the confines of this study did not explore how treatment recommendations may have been impacted by discrimination that exists across Black women’s reproductive health in the United States (VanNoy et al., 2021).

Although talking about the hysterectomy and what influenced their decision could be emotionally challenging for some women, the women who participated in the study were eager and committed to sharing their lived experiences to add their voices to the research to address inequities in fibroid treatment. No barriers were experienced with recruitment and all study criteria were met and analyzed as planned. Each woman’s perspective was unique to their lived experience and provided triangulation of the data from various points of view. While each woman shared similarities based on gender, race, and the lived experience of having an invasive abdominal hysterectomy for benign fibroid within the past 16 years, a limitation to interpretation exists due to possible variations in background, education, income, childless women and women who have at least one child, and other individual differences inherent to phenomenological studies (see Patton, 2015). It must also be acknowledged that my experience with the phenomenon could present researcher bias.

As a Black woman who had an invasive abdominal hysterectomy for benign fibroids over 20 years ago, I remained aware of any potential researcher-induced biases that could influence the course of my study. I bracketed my experience with the phenomenon by taking field notes during each interview. Additionally, I wrote reflective and journal notes and reviewed the audio-video recording of the interviews and real-time verbatim transcripts to ensure that my efforts remained unbiased. To preserve the credibility and trustworthiness of the study, before the interviews, I did not share my personal history with the phenomenon to prevent unintentional influence on answers to the research. As planned, the verbatim transcript and emerging themes were validated by participants to establish the data's accuracy, credibility, transferability, and validity.

Recommendations

Women who undergo an invasive abdominal hysterectomy have higher morbidity and mortality rates due to complications (Katon et al., 2019). As discussed in Chapter 2, numerous research studies show that Black women are 4 times more likely to undergo an invasive abdominal hysterectomy than women of any other race. Numerous quantitative studies have examined various factors such as age, race, obesity, and insurance status (Aninye & Laitner, 2021). Empirical evidence suggests a racial disparity in Black women's treatment for benign fibroids (Zaritsky et al., 2019). However, researchers still do not know why the disparity exists. There are very few peer-reviewed qualitative studies that shine a light on the lived experiences of the population most affected or further explore the choices and influences that lead Black women to decide to have an invasive abdominal hysterectomy for benign fibroids.

Further study is needed to understand why Black women are 4 times more likely to receive the treatment of invasive abdominal hysterectomy for benign fibroids. The Black women in this study were only given the treatment option of an invasive abdominal hysterectomy. Research must continue to add to the literature by adding the voices of those most affected but must also move beyond to learn why doctors are 4 times more likely to recommend the treatment of an invasive abdominal hysterectomy to Black women.

In the United States, discrimination has been well-documented in Black women's reproductive health. Future research should explore the relationship between treatment recommendations and race to promote transparency in fibroid treatment and provide a deeper understanding of the treatment disparity. Future research should include a review of clinical practices and an interview of both the patient and the doctor to discover commonalities or barriers in clinical management that limit treatment options for Black women.

Findings of numerous studies also show that Black women are significantly less aware of minimally invasive treatment options and lack knowledge about postsurgical effects. These doctor-patient education and communication gaps play a large role in the treatment disparity (Riggan et al 2021). While managing severe symptoms and being told by their doctor that the recommended treatment option will end their ability to conceive, many of the women in this study reported immense pressure to make a decision or to actively try to get pregnant before the progression of their fibroid disease further hindered their ability to do so. Many of the women reported feeling like they did not have enough information and needed more time to make a decision. As discussed by ACOG best practices, ob-gyns should provide thorough patient education and conduct ongoing shared patient-physician communication and decision-making. Based on the findings of this study, it is recommended that ob-gyns implement earlier discussion and initiation of an agreed treatment plan with set follow-up intervals so that the women do not feel rushed and overwhelmed with managing severe symptoms, learning of their treatment recommendation, and feeling the pressure to quickly decide or conceive a child.

Many of the women in this study stated that they felt pressured by their doctors to decide quickly. However, all of the women in this study were diagnosed at least 6 months or more before treatment recommendation and the progression of their fibroid disease was being monitored by their doctor. During that monitoring period, the women could have benefited from being educated about treatment options and could have engaged in fertility planning, and ongoing treatment planning discussions with their doctor or medical team. More efficient use of the monitoring period would have allowed for the women to be fully educated, get answers to questions, and seek a second opinion if desired. The results of this study indicated that the women desired a more patient-centered, shared-decision approach. They wanted to participate in ongoing discussions about treatment options that aligned with their fertility goals and have time to process the information, especially if alignment with their fertility goals was not possible. Early initiation of this shared decision patient-centered approach would have led to enhanced doctor-patient engagement and more transparency in clinical decision-making for Black women. Instead, the women were left feeling emotionally stressed and rushed when their doctor finally decided to terminate monitoring of their fibroids and provided the treatment recommendation of an invasive abdominal hysterectomy.

As found in key research studies about the treatment of abdominal hysterectomy, approximately 50% of the participants live with psychosocial impacts (VanNoy et al., 2021). Since Black women are the population 4 times more likely to undergo an invasive abdominal hysterectomy, these residual psychosocial impacts largely affect Black women. There are limited studies on the psychosocial impacts of hysterectomy in any population. Most fibroid treatment studies do not consider or explore the psychosocial context (Riggan et al., 2021). Further, most fibroid treatment studies do not explore choices, decisions, influences, social structures, and provider communication. Most fibroid studies are medical in nature and focus on the medical benefits and improved quality of life measured by the absence of severe symptoms (Riggan et al., 2021; Yu et al., 2018).

Fibroid treatment options are a personal sensitive decision that may be emotionally difficult for some women. The participants in this study reported that they suffered psychosocial impacts about desiring a child after the hysterectomy or suffered medical postsurgical effects of having a hysterectomy with ovary removal resulting in menopause. Similarly to the findings of a few other studies, many of the women in this study reported postsurgical psychosocial impacts including sadness, depression, weight gain, brain fog, sadness, distrust of their doctor, and decisional regret at times. The women reported that their doctors have deemed many of the postsurgical side effects that they are experiencing as unrelated. Many of these variables were themes that emerged and were analyzed in this study. Therefore, the exploration of these factors may be pivotal in learning why Black women often delay treatment or why the disparity exists.

Further research is needed on the use of counseling to improve psychosocial outcomes for women faced with the decision of having to undergo an abdominal hysterectomy. Counseling may further inform the reason for the health disparity as well as areas for improvement in fibroid treatment management. Fibroid treatment outcomes must no longer just be measured from a medical perspective but must include the interconnected medical and mental factors experienced by the patient as many psychosocial factors impact overall health (Schwab & Margaritis, 2020). Psychosocial and medical education and preparation should be equally addressed for the best outcomes in whole woman health for Black women and women of all races.

Implications

The results from this study exploring the influences, choices, and decisions of Black women who had an abdominal hysterectomy may provide social change implications for additional research on the lived experiences of the population most affected by the treatment disparity. The potential impact of the positive social change includes early initiation of patient-doctor communication and planning, increased awareness and education programs focused on educating Black women about all treatment options including minimally invasive treatments, and the incorporation of counseling to address psychosocial outcomes in the clinical practice of fibroid treatment management.

At the individual level, this study adds the lived experience of Black women to the scant body of research featuring their voices. Hearing directly from the population affected provides rich detailed information that could not be otherwise captured. It provides insight into the choices, influences, and decisions that each woman made. The women in the study indicated that they desired more planning, communication, and shared decision-making in collaboration with their doctor to meet their personal goals. The data collected reinforce that more ongoing ob-gyn communication and interaction are needed. On an organizational level, findings provided insight into changes that can be made across best practices in clinical practice with the early initiation of a continuum of services including fertility planning, treatment planning, fibroid treatment education and awareness, education about postsurgical effects, and counseling to improve psychosocial and medical outcomes.

Analysis of the data revealed commonalities that provided additional data to confirm or disconfirm assumptions about the health disparity. Social change is a slow process and organizational and societal change is the most difficult and will take the longest to show effectiveness. Moreover, practices in fibroid management, as well as treatment rates for Black women have not changed in over 2 decades. If implemented as a best practice, early planning and education across obstetrics-gynecology practice can lead to improved awareness for Black and in time, a shift in a treatment disparity that has barely changed in over 2 decades. Although researchers do not know why Black women have higher rates of fibroids, the early initiation of fibroid treatment awareness and education for Black women and providing timely access to the latest minimally invasive procedures for the treatment of benign fibroids can reduce the treatment disparity.

Conclusion

This study focused on the lived experiences of Black women who decided to have an abdominal hysterectomy for benign fibroids. Similarly to the research findings of key studies, the Black women in this study were given the treatment recommendation of invasive abdominal hysterectomy as their only option. This study confirmed previous research and explored and identified common themes that emerged across participants that may further be linked to causal factors for the disparity. The study added to the scant body of research about Black women diagnosed with benign fibroids. The findings of this study go beyond comparing Black to White women; they provide actual context to the lived experiences of Black women by describing what treatment options they were given, what knowledge they had about alternatives, and what influenced their treatment decisions (i.e., desire to have children, social supports, the severity of symptoms or family history of cancer). The findings provide rich data on the emotional stress that participants experienced before surgery and the lack of knowledge they had about postsurgical effects.

The findings also illuminate something rarely mentioned in the research: the postsurgical psychosocial impacts of having an abdominal hysterectomy for benign fibroids. The voices of Black women, the population disparity affected, is barely present in fibroid research (Zota & VanNoy, 2021). Very few qualitative fibroid treatment studies provide this level of rich detailed data from Black women with lived experience. This study confirmed other key studies that point to the need for additional culturally appropriate education and awareness programs about fibroid treatment specifically for Black women.

This study illuminates the need for earlier initiation, shared planning, decision-making, and ongoing communication between patient and doctor as outlined in the Recommendations section of this chapter. Further, this study provided added context by highlighting the importance of advocating for more attention to the psychosocial impacts and the need for research on the use of counseling as part of the ongoing treatment plan to address not just the medical aspects of treatment, but acknowledge the psychosocial impacts associated with the burden of the life-altering decisions associated with fibroid treatment ultimately to further reduce the disparity for Black women.

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Appendix A: Recruitment Flyer

FIBROID TREATMENT RESEARCH STUDY

BLACK WOMEN WHO HAD AN ABDOMINAL HYSTERECTOMY

Let your voices be heard – We Need You!

You may be eligible to participate in a research study to share your experiences with having an abdominal hysterectomy for benign fibroids.

Purpose: This study will explore your perspectives and experiences from the time of diagnosis with benign fibroids to the abdominal hysterectomy procedure. You will be asked to share what factors influenced choices and decisions and led you to decide to have an abdominal hysterectomy as treatment for benign fibroids.

Eligible Requirements:

- You must be 18 years or older
- You must self-identify as a Black or African American woman
- You must have undergone an abdominal hysterectomy procedure requiring an abdominal incision
- Your abdominal hysterectomy must have taken place in the past 16 years (2006 – 2022)

Participants will be asked to:

- Read and e-sign Confidentiality and Consent form
- Engage in 45 to 60-minute audio-video interview

Risks and Benefits Associated With this Study:
A hysterectomy is a sensitive, personal decision so participating in this study may involve some risk of emotional discomfort which may become challenging for you. Participation in this study is voluntary and you may decide to not to complete the interview at any point during the interview. Your interview will be kept confidential. The voices of Black women are barely present in fibroid treatment research. Findings of this study may further provide implications for research focused on educating Black women about treatment procedures that are less invasive than an abdominal hysterectomy.

Compensation:
An incentive of a $15 Amazon electronic gift card will be provided to the participant at the completion of the interview. Individuals interested, please contact
[redacted]

Appendix B: Prescreening Questionnaire

1. Are you at least 18 years old?
2. Do you self-identify as Black or African American woman?
3. Have you had an abdominal hysterectomy for benign fibroids in the past 16 years (2006 – 2022)?

Appendix C: Demographic Questionnaire

1. Please state your name. ____

2. What is your selected pseudonym for this interview? _________________________

3. What is your age? ____

4. Do you have any birth children? ______

   If yes, how many? ______

5. In what year were you first diagnosed with benign fibroids? ______

6. In what year did you have an abdominal hysterectomy for benign fibroids? ______

Appendix D: Semistructured Interview Questions

Social Ecological Model Microsystem, Macrosystem, and Chronosystem

1. Please share with me, what were your thoughts about fibroid treatment when you were first diagnosed with fibroids?
2. Please share what your thoughts were during the period between your diagnosis and the hysterectomy?
3. How old were you at the time of your abdominal hysterectomy?

Health Belief Model Perceived Benefits, Perceived Severity, and Cues to Action

4. Prior to your hysterectomy, what did you know about less invasive procedures for the treatment of benign fibroids, and how did you feel about those options?
5. How would you describe your relationship with the doctor that recommended that you undergo a hysterectomy?

Social Ecological Model Microsystem, Macrosystem, and Chronosystem

6. Please describe why other treatment options were not a good fit for you?
7. What factors did you consider prior to deciding to have an abdominal hysterectomy?
8. How did those factors influence your decision to have a hysterectomy?

Health Belief Model Perceived Benefits, Perceived Severity, and Cues to Action

9. Please share with me your thoughts and feelings about your experiences, including the decisions you made about undergoing a hysterectomy.
10. What is the best part about having a hysterectomy?
11. What has been the difficult part about having a hysterectomy?

Social Ecological Model Microsystem and Macrosystem

12. What advice do you have to share with other women specifically about undergoing an abdominal hysterectomy?
13. Please share any feelings or thoughts about your participation in this research study.