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Mental Health in Black Women With Endometriosis-Related Symptoms During COVID-19

Anjanette Jaye Blunt
Walden University

Walden University

College of Allied Health

This is to certify that the doctoral dissertation by

Anjanette Jaye Blunt

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Review Committee
Dr. Delinda Mercer, Committee Chairperson, Psychology Faculty
Dr. Brent Robbins, Committee Member, Psychology Faculty
Dr. Benita Stiles-Smith, University Reviewer, Psychology Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
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Abstract

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MS, Walden University, 2019

MA, Webster University, 2004

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Dissertation Submitted in Partial Fulfillment

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Doctor of Philosophy

Psychology

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Abstract

Endometriosis is an incurable chronic illness impacting 190 million women worldwide. Despite the prevalence of this painful disease, research addressing how it affects Black women in the United States was limited. Research addressing this phenomenon during the COVID-19 pandemic was further limited. The purpose of this qualitative study employing an interpretative phenomenological analysis was to understand the mental health of Black women with endometriosis-related symptoms during the COVID-19 pandemic and how having the illness during the pandemic might have impacted individuals in this population. The strong Black woman schema and biopsychosocial model were the theoretical foundations for the study. Data were collected from semistructured interviews with eight Black women with endometriosis. Four major themes emerged from coding and thematic analysis: health, life with endometriosis, the U.S. health care system, and the nature of being a Black woman in the United States. Findings may be used to enhance awareness of Black women's experiences with endometriosis while facing cultural stigmas, systemic disparities, COVID-19 restrictions, and other barriers. Findings could also encourage positive social change through increased funding for endometriosis research and resources to educate providers, raise public awareness, and provide culturally appropriate support and treatment for Black women.

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Dedication

I dedicate this body of work to God first because, without Him, nothing is possible. I am thankful that He has put me on this path to helping others and finally finding my purpose in life. I also dedicate this work to my parents. They have always encouraged and supported me in everything I have done and have always been there for me, no matter the occasion. I am forever grateful for them and their unconditional love, loyalty, and protection; I love them more than they know. I dedicate this study to every woman who has ever struggled with endometriosis. I pray that your healing journey is fruitful, and I pledge to continue being an advocate and fighting for advancing this complicated and misunderstood disease. Most importantly, I dedicate this research literature to my daughter, Jayla. She has always been my motivation for achieving goals in life and is the primary source of my inspiration in this journey called life. Jayla means different things depending on the place of origin and source of interpretation. The words “ascend,” “God will protect,” and “warrior” are all words that have been accurately associated with her name. However, primarily, she was born a warrior, and she will forever be a warrior in my eyes. I am intrigued by her resilience, strength, and intelligence. She is unequivocally a powerful force to be reckoned with! I am so honored and blessed to be her mother and even more blessed to call her my daughter. She has been the motivation behind my major life’s decision, including the topic of this paper, and is the only reason I could complete this work. Jayla, I love you unconditionally and always. May God bless you, keep you safe, and shine His light on your life’s path.

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First, I acknowledge and give thanks to God. He is my rock, my provider, and my light in life. Also, I want to thank my family and friends for being there and encouraging me to do my best, keep going, and never give up! I want to thank my dear friend, peer, colleague, and cohort comrade, Marion Kwoba-Rexella Pickering. She has been my guide and source of strength throughout my entire academic journey at Walden, and I am eternally grateful to be able to call her a friend. Marion, I love you to the moon and back! I also thank my friend and colleague, Ashley J. Williams. She has checked in with me almost daily since I began my dissertation journey, inspiring me to continue working and to get this thing done! I am so blessed to have met Ashley. She is a breath of fresh air and has breathed life into my dissertation journey by consistently energizing me and providing emotional support. Ashley, I love you, my friend! I would like to acknowledge and thank the entire Walden University doctoral committee. I give my sincerest gratitude for the demanding work that the committee has done. I know it could not have been easy to do such meaningful work through COVID-19 challenges. I thank my chair, Dr. Delinda E. Mercer, and my cochair, Dr. Brent D. Robbins. I am thankful that they are a part of the committee for my capstone study and appreciate the time, expertise, and effort they have put into supporting me throughout this entire dissertation trek. I would not have made it this far without their guidance and recommendations. I also want to acknowledge and thank the university research reviewer, Dr. Benita Stiles-Smith, for her dedication to ensuring the quality of my work and providing feedback to make it a quality and impactful body of work. I thank the chief academic officer and provost, Dr. Sue Subocz, because this work is fruitless without your approval.

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Chapter 1: Introduction to the Study

This study was designed to facilitate a deeper understanding of the perceived experiences of Black women living in the United States regarding their mental health needs while having endometriosis-related symptoms during the COVID-19 pandemic. Research on endometriosis among Black women was limited in the United States and even more limited during the COVID-19 pandemic. Black women have been understudied in research related to endometriosis and have been frequently underdiagnosed or undiagnosed with the illness (Mende-Siedlecki et al., 2019). Moreover, Black women in the United States have faced inherent racial and ethnic disparities that persist in the American health care system, which the COVID-19 environment has exacerbated (Walton et al., 2021). Black Americans have contracted COVID-19 at higher rates and have been more susceptible to complications or death due to the virus (Walton et al., 2021). Walton et al. explained that Black women are more likely to die once they contract the disease due to the lack of access to affordable health care and bear a financial and mental burden related to the COVID-19 pandemic and systemic racism that intersects with other oppressive systems.

I did not find any studies in the United States related to Black women and how they perceived their level of care while having endometriosis symptomology or how the illness impacted their mental health during the COVID-19 pandemic. Therefore, I researched Black women’s experiences with endometriosis in the United States and how they managed their endometriosis-related symptoms during the COVID-19 pandemic. I aimed to learn how participants viewed their care level during the pandemic. I sought to understand what factors might contribute to some Black women not seeking mental health care while experiencing endometriosis symptoms during the COVID-19 pandemic to identify themes in their narratives, including those that aligned with the biopsychosocial model or Black feminist theory. This chapter of the study provides the background information on endometriosis and how it impacts women in the United States, the racial and ethnic disparities in the health care system, and how women have coped with symptoms (i.e., chronic pain and infertility issues) during the COVID-19 pandemic. This chapter section also addresses the problem statement, study purpose, research questions, theoretical framework, definitions, assumptions, and limitations.

Background

Research has found that women are twice as prone to experience depression as men (Bacigalupe et al., 2020; Richards, 2021). Also, Black people are 30% more likely to have grave psychological illnesses than Whites (Centers for Disease Control and Prevention [CDC], 2005). Black people are disproportionately more prone to experience social situations that increase their chances of developing a mental disorder (but are less likely to receive treatment) than Whites (Evangeline et al., 2011). Black women face harmful institutional mental health disparities as both women and Black individuals. Black women are one of the most undertreated and underserved groups in the United States; they are half as likely to seek treatment as White women (Richards, 2021). Also, research has shown that Black women are often undiagnosed or misdiagnosed with endometriosis, which causes delays in treatment for their chronic pain and other symptoms (Facchin et al., 2018). Despite multiple studies regarding how endometriosis impacts women worldwide, there were few studies addressing how endometriosis affects Black women in the United States. Shade et al. (2012) stated that only two other studies had been done addressing endometriosis in the African American female population; not much had changed since Shade et al. authored this article.

Deficits in mental health care for Black women have been compounded by the lack of research on this racial minority group during the COVID-19 pandemic. Walton et al. (2021) stated that the COVID-19 pandemic had substantially impacted many Black Americans and pointed out that Black Americans account for most pandemic-related deaths across all age categories. Walton et al. emphasized that Black women faced physical, financial, and mental difficulties during the pandemic. Moreover, systemic racism is increasingly causing Black women to have conditions such as diabetes, breathing illnesses, and hypertension, leading to a higher susceptibility to COVID-19 contraction, a more complicated course of the disease, and death (Bailey et al., 2020; Bailey & Moon, 2020; Reyes et al., 2020). Stressors related to COVID-19 are placing additional distress on these women's mental health and overall wellbeing (Walton et al., 2021). Black women are experiencing elevated levels of anxiety, depression, stress, feelings of hopelessness, fear, and suicidality related to isolation, uncertainty, and other issues (Serafini et al., 2020; Xiang et al., 2020). This reality intensifies psychological stressors and health disparities that already existed for this racial minority group before the pandemic (Walton et al., 2021).

Multiple studies have attributed disparity among Black women in research and treatment to racial or ethnic biases in the health care system (Allen et al., 2019).

However, there were no peer-reviewed studies addressing how Black women in the United States had experienced endometriosis-related symptoms during the COVID-19 pandemic. Black feminist thought or theory, namely the strong Black woman schema (SBWS) or superwoman schema (SWS), provided a context to understand how women might perceive their mental and physical health care in the United States and their proneness for seeking treatment. The SBWS or SWS schema (Abrams et al., 2019; Carter & Rossi, 2019; Green, 2019; Liao et al., 2020; Stanton et al., 2017; Watson-Singleton, 2017) and its impact on Black women's mental health were paramount to understanding their treatment, perceptions of treatment, and probability of seeking and remaining in treatment in the United States.

The SBWS has been related to racial discrimination and adverse physiological and psychological effects on Black women. Watson-Singleton (2017) researched how Black women are often seen as superhuman, a perception that ties to their roles as enslaved people. Although the superwoman concept was partly motivated by Black women's strides to mitigate negative societal prejudices and images of their womanhood (i.e., the "mammy," "welfare queen," or "Jezebel"; Woods-Giscombe, 2010), it has developed into a negative and maladaptive coping mechanism for Black women. Watson-Singleton found that the SBWS is related to reduced perceived emotional support and increased psychological distress. The current ideology is that Black women have extraordinary strength in their multiple roles, including caring for others (Liao et al., 2020). Liao et al. (2020) stated that Black women are socially encouraged by their parents, the media, and their communities to internalize and embrace the SBWS. Liao et al. explained that economic, racial, and structural inequities perpetuating the SBWS need to be researched and eradicated. Abrams et al. (2019) confirmed an existing relationship between psychological distress and Black women internalizing the SBWS. Abrams et al. identified silencing and externalization of self-perceptions as crucial factors in depressive symptoms related to the schema.

Allen et al. (2019) discussed how racial discrimination and the SWS subscales (obligation to present an image of strength, obligation to suppress emotions, resistance to vulnerability, intense motivation to succeed, and obligation to help others) are connected to the allostatic load. Similarly, Stanton et al. (2017) found that more vigorous promotion of the SBWS ideology and increased social media use was associated with lower self-esteem and poorer mental health. Allen et al. demonstrated that the relationship between allostatic load and racial discrimination is nonlinear, the SWS factors alter the relationship between allostatic load and racial discrimination, and the impact of the SWS varies on the relationship between allostatic load and racial discrimination. The findings indicated a relationship between the four SWS scales and racial discrimination. Obligations to display images of strength and suppress emotions were protective. Also, the intense motivation to succeed and the commitment to help others increased the health risk associated with encountering racial discrimination. This study demonstrated social stress's role in physiologic systems through the body's stress responses and highlighted the need for researchers to understand how social determinants impact racial health inequalities.

Allen et al.’s (2019) findings indicated that more research should be done in the United States to understand Black women and their perceptions of the American health care system and the level of care they receive for their mental health. The current study focused on an unexplored topic: Black women and endometriosis symptomology and the impact of the symptoms on Black women’s mental health during the COVID-19 pandemic. This study addressed the topic of Black women and their perceived experiences with having endometriosis-related pain during the COVID-19 pandemic, particularly how this pain had impacted and might continue to impact their mental health. I strove to enhance the public’s awareness of the degree to which Black women believed that their mental health needs had been met in the United States during the pandemic, focusing on the population of Black women with endometriosis, an understudied group.

Problem Statement

Endometriosis affects many women globally from all ethnic and racial backgrounds. However, research on Black women with endometriosis in the United States was limited, particularly its effect on Black American women during the COVID-19 pandemic. Statistics showed that the disease impacts the health of about 190 million women of childbearing age (World Health Organization, 2021a). Despite this number, endometriosis patients continue to endure the disease’s negative implications, including chronic pain, for up to 11 years before being diagnosed due to the lack of noninvasive diagnostic procedures (Parasar et al., 2017). Research also showed that endometriosis patients are prone to higher depression and anxiety rates than their unaffected counterparts (Gambadauro et al., 2019; Laganà et al., 2017). Compounding this issue, restrictions and the mental strain that the pandemic has caused have negatively impacted endometriosis patients' overall health (Ramos-Echevarría et al., 2021; Rowe & Quinlivan, 2020). Furthermore, Black Americans account for the most COVID-19-related deaths (Walton et al., 2021). Also, this phenomenon is complicated by Black women facing institutional racism that leads to diseases and higher levels of mental distress, including suicidality (Bailey et al., 2020; Bailey & Moon, 2020; Reyes et al., 2020).

As-Sanie et al. (2019) highlighted that endometriosis is underresearched and underfunded, which limits the development of more effective diagnosis and treatment criteria. Although researchers had explored the impact of endometriosis on the mental health of affected patients, the topic had not been investigated from a race-based perspective. Similarly, researchers had assessed the association between endometriosis and COVID-19. However, researchers had not factored in the effects of race on the variables, particularly how Black women perceive their level of care for their mental health related to their symptoms. The impact of endometriosis-related symptoms on Black women's mental health had been underresearched before and during the COVID-19 pandemic; research of this nature was particularly limited in the United States.

Moreover, Farland and Horne (2019) found that historical perceptions of endometriosis diagnosis have minimized its association with Black women, and Bougie et al. (2019) stated that African American women's diagnoses with endometriosis are fewer than White women's diagnoses. However, because research was limited on Black women who have endometriosis in the United States, it remained unclear how endometriosis symptoms had impacted their mental health during the COVID-19 pandemic. There was research on how COVID-19 affected the physical and mental health of non-Black women or women living in other countries (Arena et al., 2021; Crispi et al., 2021; Demetriou et al., 2021; Evans et al., 2021; Moazzami et al., 2021; Ramos-Echevarria et al., 2021; Rosielle et al., 2021; Rowe and Quinlivan, 2020; Schwab et al., 2021). However, no peer-reviewed study addressed how COVID-19 has impacted Black women's mental health who have endometriosis symptomology.

As a result of racial and ethnic health care disparities and gaps in research on Black women with endometriosis, Black women continue to be understudied, undertreated, underdiagnosed, and misdiagnosed. This reality leads to perpetual devaluation and dismissal of understanding how Black women perceived their mental health treatment in the United States during the COVID-19 pandemic. This overlooked area of research contributes to sustaining the potentially harmful physical and psychological pain and suffering Black women have endured and continue to endure in an inequitable U.S. health care system.

Purpose of the Study

The purpose of this study was to explore and gain a deeper understanding of the mental health of Black women with endometriosis-related symptoms during the COVID-19 pandemic and how having the illness during the pandemic might have impacted individuals in this population. No studies had addressed Black women's perceptions of how their mental health needs related to endometriosis symptoms had been addressed during the COVID-19 pandemic in the United States. Therefore, there was no way to know whether Black women with endometriosis symptomology had similar or different perceptions of how their mental health needs had been met during the pandemic or whether those perceptions were similar to non-Black women's perceptions. There was also no way to understand what biological, psychological, social, economic, or other factors might have influenced Black women's perceptions or behaviors. The current study addressed these gaps in existing research. I collected data from semistructured interviews with eight Black women citizens of the United States with endometriosis to better understand their perceptions regarding their experiences and level of care for their mental health related to endometriosis symptomology during the COVID-19 pandemic. The study was conducted with American Black women from 18 to 40 years old.

Research Questions

The following research questions (RQs) were used to guide the study:

RQ1: What are the lived experiences of Black women with endometriosis during the COVID-19 pandemic?

RQ2: How do Black women manage their endometriosis-related symptoms during the COVID-19 pandemic?

RQ3: How do Black women perceive their mental health and medical care for endometriosis-related symptoms during the COVID-19 pandemic?

Theoretical Framework

Black feminist theory by Collins (1990) guided this study, while the biopsychosocial approach by Engel (1977) informed it. These theories provided a framework that aligned with the study's topic, methodology, and research questions for the participant population. The social problem that prompted this study was that Black women have experienced disparities in the U.S. health care system and continue to be an understudied, underresearched, and undertreated population. This theme of intersectionality implies that Black women might have experienced numerous challenges with endometriosis during the COVID-19 pandemic. Collins addressed the intersecting nature of oppression Black women face in her Black feminist thought theory, which was categorized as a “critical social theory.” This theory addressed the overarching phenomenon of the study about how sexism and racism jointly and perpetually serve to disadvantage Black women in the United States.

This study was also guided by the SBWS (or SWS) of Black feminist theory and its five core themes: obligation to present an image of strength, obligation to suppress emotions, resistance to vulnerability, intense motivation to succeed, and duty to help others (see Allen et al., 2019). The biopsychosocial model supported the premise that focusing on the everyday needs of all women with endometriosis and considering the person’s biological, psychological, and social experiences and individual needs is more valuable than the biomedical approach, which focuses solely on the disease. These theories were utilized to analyze how health care providers consider Black women’s biopsychosocial needs (including cultural influences, such as the SWS), perceived endometriosis symptoms, and perceived mental and physical health care levels related to endometriosis symptoms.

Nature of the Study

To answer the research questions, I used a qualitative approach. The research design included an interpretative phenomenological analysis (IPA) to explore the participants’ lived experiences. Data collection and observation were achieved through semistructured interviews with eight participants. The participants were selected through purposeful and snowball sampling. Sample questions that I asked in the interview included the following: “How has your experience with living with endometriosis during COVID-19 been?” “Have you been diagnosed with any mental illness(es) related to your endometriosis pain or symptoms, and if so, what illness(es)?” “How have you managed to deal with your endometriosis symptoms during COVID-19?” I aimed to explore, analyze, and interpret perceived phenomena according to reported accounts of lived experiences instead of preexisting theoretical preconceptions (see Smith & Osborn, 2015). To understand whether the women experienced challenges related to the SBWS, I asked questions such as the following: “Do you feel the need to suppress your emotions? If so, please explain;” “Do you feel like you resist vulnerability at times? If so, please explain.”

Phenomenology supports detailed inquiry, making it a suitable design to explore a topic extensively (Neubauer et al., 2019). An IPA enables an in-depth understanding of individuals’ lived experiences while considering social-cultural contexts, including how the experience affects participants’ lives. Smith and Osborn (2015) illuminated the usefulness of IPA for analyzing complex and emotionally charged phenomena such as pain, which they described as “elusive, involving complex psychosomatic interactions and difficult to articulate” (p. 41). Endometriosis is a chronic illness that often causes those with it to experience severe, cyclical somatic and psychological symptoms, and Black women are an understudied population in endometriosis research. Therefore, IPA was an appropriate method for exploring the participants’ concerns and making sense of their accounts from a psychological perspective (see Larkin et al., 2006). IPA was an appropriate method for understanding how Black women with endometriosis have perceived the quality of their physical and mental health care needs during the COVID-19 pandemic. The study included an unfolding and compelling narrative: an active, experiential account of responses; a careful analysis of participants’ words; and mindful consideration of convergence and divergence (see Nizza et al., 2021).

Definitions

This study contained medical and technical terms and concepts. Therefore, the following terms and concepts are defined for clarification:

Ascites: The pathological accumulation of fluid inside the peritoneal cavity (Gungor et al., 2011).

Bilateral salpingo-oophorectomy: Surgical removal of a uterine tubes and ovaries (Dorland, n.d.-a).

Biographical disruption: The disruption of the structures of everyday life and the forms of knowledge that underpin them (i.e., chronic illness is a biographical disruption; Cole et al., 2021).

Biomedical approach: A model that views disease as an entity independent of the affected person or population (Green & Johnson, 2013).

Biopsychosocial theory: A theory that relates how a range of factors can interrelate to affect physical and mental health, proposing a broader approach to health care (Green & Johnson, 2013; Havelka et al., 2009).

Chronic fatigue syndrome: Persistent, debilitating fatigue lasting longer than 6 months, with other known medical conditions having been ruled out by clinical diagnosis, accompanied by at least four of the following: significantly impaired short-term memory or concentration, muscle weakness, pain in multiple joints without swelling or redness, sore throat, tender lymph nodes, headaches, unrefreshing sleep, and malaise that lasts more than 24 hours following exertion (Dorland, n.d.-b).

Chronic pelvic pain (CPP): A syndrome consisting of nonspecific pain in pelvic organs or tissues that has been continuous for at least 6 months and is not caused by malignancy, infection, or other obvious pathology (Dorland, n.d.-c).

Dyschezia: Bowel-related pain; difficult or painful defecation (Tomassetti et al., 2021; Dorland, n.d.-d).

Dysmenorrhea: Painful menstruation (Dorland, n.d.-e).

Dyspareunia: Difficult or painful sexual intercourse (Dorland, n.d.-f).

Dysuria: Urinary tract related pain; painful urination (Tomassetti et al., 2021; Dorland, n.d.-g).

Endometriosis: A disease characterized by the presence of endometrium-like epithelium and stroma outside of the endometrium and myometrium. Intrapelvic endometriosis can be located superficially on the peritoneum (peritoneal endometriosis), can extend 5 mm or more beneath the peritoneum (deep endometriosis), or can be present as an ovarian endometriotic cyst (endometrioma; Zegers-Hochschild et al., 2017).

Fertility: The capacity to establish a clinical pregnancy (Tomassetti et al., 2021; Zegers-Hochschild et al., 2017).

Fibromyalgia: Pain and stiffness in the muscles and joints that either is diffuse or has multiple trigger points (Dorland, n.d.-h).

FODMAP diet: A diet composed of fermentable oligosaccharides, disaccharides, monosaccharides, and polyols (Leonardi et al., 2020).

Hemorrhage: The escape of blood from the vessels; bleeding (Dorland, n.d.-i).

Hysterectomy: The operation of excising the entire uterus, performed either through the abdominal wall or through the vagina (Dorland, n.d.-j).

Infertility: A disease characterized by the failure to establish a clinical pregnancy after 12 months of regular, unprotected sexual intercourse or due to an impairment of a person’s capacity to reproduce, either as an individual or with their partner (Tomassetti et al., 2021; World Health Organization, 2021b; Zegers-Hochschild et al., 2017).

Irritable bowel syndrome: A common, chronic, noninflammatory condition characterized by abdominal pain and altered bowel habits (diarrhea or constipation or both) but no detectable pathological change; there may be spasms of the intestinal muscles (Dorland, n.d.-k).

Laparoscopy: Examination of the interior of the abdomen by means of a laparoscope (Dorland, n.d.-l).

Metasynthesis: A systemic review of qualitative research reports in which the findings are not only a synthesis of the primary research findings but also an interpretation of them and can be useful for evidence-based practice (Souza et al., 2011).

Mittleschmerz: Pain related to ovulation, noncyclic pelvic pain (Tomassetti et al., 2021).

Morbidity: A diseased condition or state (Dorland, n.d.-m).

Ovarian cyst: A cyst of the ovary proper (Dorland, n.d.-n).

Painful bladder syndrome: Interstitial cystitis that covers a heterogeneous spectrum of abnormalities with bladder pain as a common symptom. Based on this, interstitial cystitis has been renamed to painful bladder syndrome, considering it one of the numerous syndromes that constitute chronic pelvic pain (Rapariz-Gonzalez et al., 2014).

Patient-centered care: Understanding illness and treatment from patients' point of view based on their experiences to understand their needs, values, and preferences in addition to depending on scientific knowledge (Geukens et al., 2018).

Pelvic inflammatory disease: Any pelvic infection involving the upper female genital tract beyond the cervix (Dorland, n.d.-o).

Psychosomatic: A disorder in which physical symptoms, such as migraine headache, lower back pain, or irritable bowel syndrome, are caused or exacerbated by psychological factors (Dorland, n.d.-p).

Secondary gain: The advantage that occurs secondary to actual or stated illness (Zadinsky & Boyle, 1996).

Uterine endometriotic implants: Fragments of endometrial mucosa transferred through the uterine tubes and implanted on the uterus, ovaries, or pelvic peritoneum (Dorland, n.d.-q).

Uterine fibroid: A leiomyoma (benign fibrous tumor) of the uterus, usually occurring in the third and fourth decades of life, characterized by multiple, firm, round, sharply circumscribed, unencapsulated, gray to white tumors that show a whorled pattern on cut section (Dorland, n.d.-r).

Assumptions

This IPA study was designed to address a gap in research by providing a deeper understanding of Black women's perceived mental health experiences with having endometriosis-related symptoms during the COVID-19 pandemic. The women participants in this study were American Black women diagnosed with endometriosis between the ages of 18 and 40. The first assumption was that the participants were honest in self-reporting about being diagnosed with endometriosis. The second assumption was that the women were truthful in responding to the demographic survey and interview questions. The third assumption was that the respondents were honest in their responses to the open-ended interview questions. The fourth assumption was that although the women participants identified as Black, their perceptions of their level of care for endometriosis-related symptoms during the COVID-19 pandemic might vary.

Scope and Delimitations

This study included eight Black women between the ages of 18 and 40 living in the United States regarding their perceptions of mental health related to endometriosis symptomology. I assessed the women's perceived level of mental health care related to having endometriosis pain and other symptoms during the COVID-19 pandemic. The participants were recruited through nonrandom, purposeful sampling, and the data were gathered through semistructured interviews. The data I used to answer the research questions were accumulated through direct investigation and a self-reported description of the mental health issues Black women with endometriosis-related symptoms experienced during the COVID-19 pandemic. I analyzed the data and used coding to identify notable events, concepts, and associated relations to produce critical themes and findings that enhanced the study's transferability and relevance to future studies. The transferability of this study was supported by the participants varying in age and socioeconomic status living in various parts of the United States. The participants were recruited from multiple sites, ensuring variety within the participant pool.

Limitations

One limitation of this study was that the results were not generalizable to all Black women in the United States with endometriosis because of the nature of the study, which addressed a small group of Black women's perspectives. Moreover, other factors, such as the women's socioeconomic status or educational level, were not considered when selecting participants. The results are likely replicable, considering that many women with endometriosis experience symptoms or mental anguish. However, the scope of the study was limited to how endometriosis impacts Black women's mental health in the United States during the COVID-19 pandemic. Another study limitation was potential participant dropout due to illness or other conflicts, obligations, or issues. A third limitation was participants' avoiding discussions about specific details of their mental conditions or physical ailments, such as infertility, due to the sensitivity of the question or topic. A fourth limitation was that religion, birthplace, and other demographic factors were not considered for this study, so it eliminated factors that might have otherwise impacted its findings. From a researcher's perspective, other potential limitations of the study included available financial resources to allocate to the research (i.e., payment of participant incentives and expenses associated with data collection) and time constraints due to other obligations.

Significance

This study is significant because it may facilitate a deeper understanding of Black women’s experiences regarding their perceptions of mental health and other health issues related to having endometriosis during the COVID-19 pandemic. I created a safe space where Black women could feel heard and have their feelings and thoughts validated, a place where they might share what they believed works best for them in health care settings. Secondly, the study may open a dialogue about the SBWS. Findings suggested how this schema might have impacted Black women’s perception of mental health treatment related to their illness during (and possibly before) the COVID-19 pandemic. Thirdly, this study contributed to furthering endometriosis research through its content and identification of limitations, which could increase the understanding of the disease, boost diagnostic and treatment innovation, and foster funding for additional research, particularly for this understudied population. In a broader sense, this study could establish the grounds for further exploration of the association between endometriosis, mental health, race, intersectionality, and the COVID-19 pandemic or other natural disasters.

Summary

This chapter introduced the purpose of the study, which was gaining a deeper understanding of American Black women’s perception of their mental health while experiencing endometriosis symptomology during the COVID-19 pandemic. I explained the study’s core components, starting with its background, which addressed how Black women are an underserved, undertreated, and understudied population, particularly involving endometriosis. Many studies had addressed diverse topics about endometriosis and how the illness impacts women, couples, and families. However, very few studies addressed how the condition affects Black women’s mental health. Even fewer studies existed on how endometriosis impacted Black women during the COVID-19 pandemic in the United States. Considering that COVID-19-related stressors increase distress in Black women, elevating their suicidal ideation, depression, stress, anxiety, hopelessness, and fear (Serafini et al., 2020; Xiang et al., 2020), a study of this nature was long overdue. The study may contribute to a foundational body of understudied research.

Overall, Chapter 1 highlighted the critical nature of the study topic and its population’s longstanding unmet needs. This chapter also included the problem statement, purpose of the study, research questions, and the theoretical foundation of the research. Chapter 2 provides an in-depth review of the literature regarding the study’s topic and theoretical foundation.

Chapter 2: Literature Review

Endometriosis is a health care issue that affects many women globally, regardless of their racial or ethnic backgrounds. Although researchers have assessed the mental health impact of endometriosis among affected persons, they have not extensively explored the impact of the disease from a race-based perspective. Additionally, some studies have assessed the association between the COVID-19 pandemic and endometriosis, but most have not considered race's role in this dynamic. Specifically, researchers have understudied the effects of endometriosis-related symptoms on Black women's mental health before and during the COVID-19 pandemic. Research inconsistencies are particularly prominent in the United States. Consequently, I aimed to explore and gain a deeper understanding of the mental health of Black women with endometriosis-related symptoms during the COVID-19 pandemic by learning their perspectives and considering cultural and biopsychosocial factors that impact them.

Statistics published by the World Health Organization (2021a) highlighted that endometriosis impacts the health of about 190 million women of childbearing age. Many endometriosis patients are forced to endure the disease's harmful effects, including chronic pain, for up to 11 years before diagnosis (Parasar et al., 2017). Parasar et al. mentioned that the effects are attributed to the lack of noninvasive diagnostic procedures, a factor that lengthens the period between the presentation of the first symptoms and diagnosis. As-Sanie et al. (2019) explained that endometriosis is underresearched and underfunded, factors that limit the development of more effective diagnosis and treatment criteria. Research has also shown that endometriosis patients are prone to higher anxiety and depression rates than those without the disease (Gambadauro et al., 2019; Laganà et al., 2017).

Additionally, studies have revealed that COVID-19 restrictions and the mental strain the pandemic caused have negatively impacted the health of endometriosis patients (Ramos-Echevarría et al., 2021; Rowe & Quinlivan, 2020). Moreover, Farland and Horne (2019) found that historical endometriosis diagnosis perceptions have minimized the disease's association with Black women. Bougie et al. (2019) affirmed this finding indicating that fewer Black women are diagnosed with endometriosis compared to their White counterparts.

Furthermore, multiple studies, such as those published by Gonçalves et al. (2016) and Moradi et al. (2014), did not indicate the participants' race. The gaps in literature related to Black women with endometriosis in the United States during the COVID-19 pandemic (in the presence of numerous studies on endometriosis) motivated the current study. The painful and incurable nature of the disease, the unknown cause of the disease, the frequency of delayed diagnosis or misdiagnosis, and existing racial disparities in the U.S. health care system are also factors that motivated this study.

The literature review chapter of this study presents a comprehensive analysis of published research to explore the many ways endometriosis impacts women. This chapter also addresses how having endometriosis during the COVID-19 pandemic impacted women. I discuss the limited research on having endometriosis symptoms during the COVID-19 pandemic, concentrating on Black women with the disease. This chapter includes a review of feminist theory, Black feminist theory, the SBWS, and the biopsychosocial model and how they align with this study. Also, it includes the literature search strategy, the study's theoretical foundation, a comprehensive literature review, and a summary and conclusion.

Literature Search Strategy

The literature search started with goal setting to define the purpose of the process. The primary goal of the literature search was to find as many peer-reviewed studies as possible exploring the mental health of Black women with endometriosis-related symptoms during the COVID-19 pandemic. The second goal was to seek out recent peer-reviewed articles on Black feminist theory, the SBWS or SWS, and the biopsychosocial model or theory. The third goal was to retrieve articles related to endometriosis symptoms and how the disease impacts women.

The search for published research on these subjects began on search engines and library databases including Google Scholar, Thoreau Multi-Database, ERIC, CINAHL, EBSCOhost Crohane Library, EMBASE, and MEDLINE. The search was restricted between 2010 and 2021 to access the most recent and relevant information; however, some older articles were relevant to the study. Additionally, the search results were filtered to only include peer-reviewed scholarly sources. The search terms and combinations of terms used to acquire the literature that is reviewed in this section included the following: *mental health*, *Black women*, *African American women*, *Black women mental health*, *African American women mental health*, *endometriosis*, *endometriosis in Black women*, *endometriosis in African American women*, *strong Black woman syndrome*, *Superwoman schema*, *Black feminist thought*, *Black feminist theory*, *quality of life*, *self-efficacy, psychosocial factors*, *biopsychosocial, biopsychosocial model, biopsychosocial theory, mental health needs, COVID-19*, *COVID-19 pandemic, Black women with endometriosis during COVID-19*, and *African American women with endometriosis during COVID-19.*

Theoretical Foundation

Black feminist theory by Collins (1990) and the biopsychosocial approach by Engel (1977) guided this study. These theories were the most fundamental approaches to creating a theoretical foundation that aligned with the research questions for the participant population: Black women. Feminist theory focuses on altering oppressive structures and facilitating action by connecting abstract ideas with tangible social issues (Lay & Daley, 2007). This theory is related to gender disparities in the U.S. health care system in which women's pain is frequently normalized, especially pain related to their reproductive systems. The normalization of women's pain was a repeated self-reported theme in much of the literature I reviewed. This systemic oppression that adversely impacts women is intensified for Black American women considering the prevalence of racial and ethnic inequities in the U.S. health care system. Second, the biopsychosocial model champions the integration of psychological, social, and biological factors in disease prevention, treatment, and study (Green & Johnson, 2013; Havelka et al., 2009). Gerrity (2001) employed the biopsychosocial perspective for understanding the physical, emotional, and existential impact of infertility on couples and proposed treatment recommendations working with women and couples coping with infertility. Infertility is a primary biological concern for women and couples coping and living with endometriosis.

Similarly, social or cultural factors, such as the SBWS, are of equal value and significance. Therefore, the influence of the biopsychosocial model, which introduced the notion of including social and psychological factors in health care, was appropriate for this study. Additionally, because chronic pain, which is frequently associated with endometriosis, is prevalent in the United States and providers have difficulty understanding and treating it (Pergolizzi et al., 2013), addressing the causation, course, and treatment of the pain from a biopsychosocial perspective was essential. Pergolizzi et al. (2013) explained that doctors’ pain management training is often insufficient. Therefore, Pergolizzi et al. endorsed a multidisciplinary approach to pain management and pointed out that the biopsychosocial approach is vital to understanding patients who suffer from chronic pain. Driscoll and Kerns (2016) also expressed that the biopsychosocial pain model is the most used modality in explaining chronic pain and treatment. To best understand the evolution of the illness and how to treat it, physicians must be able to relate to and communicate with patients within an informed biopsychosocial context; physicians must understand their patients.

Overall, the biopsychosocial theory considers the connection between mental health, illnesses, and social or cultural factors in individuals’ lives and promotes the need for collaborative pain management among physicians, mental health professionals, and other health care providers. Given the phenomenological nature of the current study, I employed the biopsychosocial and Black feminist theories as a foundation for understanding and raising awareness about how Black women perceive their mental health and level of care related to their endometriosis symptoms in the United States during the COVID-19 pandemic. Although an IPA facilitated a more profound understanding, framing the research questions within the theoretical foundations of Black feminism and the biopsychosocial paradigms aided in conceptualizing Black women's perceived experiences and presenting culturally and socially sensitive recommendations for treatment.

Feminist Theory

According to Lay and Daley (2007), a small component of the feminist movement developed the feminist theory, which challenges priorities, traditions, and methodologies in all life aspects. The theory was used to reassess the methods and concepts used across and within academic disciplines. Lay and Daley explained that the feminist theory provides a women-centered viewpoint for understanding the issues women face within contemporary society. This theory bases its arguments on feminism, a global view that prioritizes women's needs and confronts systemic gender-based injustices. This perspective necessitates viewing family, individuals, organizations, and groups in ethnic, political, economic, social, and cultural contexts, generating a contextual intersection that produces the potential for gendered oppression in relationships. Feminist theory is used to understand power differentials between women and men and the association of power to oppression evolution. The theory is also used to foster social change that stops oppression.

Often, individuals associate feminist theory with women's rights. However, women's rights fail to acknowledge that there is no single monolithic feminist approach. Viewing feminist theory as synonymous with women's rights is a reductionistic and oversimplified view of feminism (Lay & Daley, 2007). Instead, there are many feministic viewpoints with different theoretical groundings. Although there are many feministic viewpoints, Lay and Daley stated that the most common types of feminist theories include Black feminism, radical feminism, lesbian feminism, cultural feminism, Marxist feminism, liberal feminism, socialist feminism, and materialist feminism. A second assumption associated with feminist theory is that women and men have different experiences. According to Lay and Daley, instead of advocating for equality, feminist theory is used to explain the differences between women and men and how those differences affect human behavior.

Although feminist theory was relevant to the topic of the current study, it did not touch upon the impact that race has on Black women who already face discrimination and oppression as women. Black feminist theory addressed this and other gaps in intersectionality that feminist theory overlooked. Therefore, I chose Black feminist theory to address this identified deficit and better align with the study’s population, research questions, design, and purpose.

Cole et al. (2021) examined the psychosocial effects of endometriosis on women’s identity. Cole et al. also explored feminist-theory-related methodologies, acknowledging that examining women’s experiences must reflect care, respect, and collaboration. The study employed a broad feminist approach that accommodated incorporating several feminist perspectives. Cole et al. noted that ethical and political feminist scholarship concerns informed their research, allowing the exploitation of relevant materials to facilitate social and cultural transformations. The study showed that women diagnosed with endometriosis experienced many barriers to appraising their relationships and identities owing to the psychological and physical impacts of the condition. The study's participants expressed that they found it challenging to maintain their feminine identities amidst embarrassing personal symptoms and infertility worries. The participants also highlighted that they struggled to obtain appropriate symptom treatment because they felt like medical professionals cast them as hysterical women. However, among the participants selected, only one was Black. Also, the study only included participants from the United Kingdom. These factors justify the gap that the current study was designed to fill.

Feminist theory offers a women-centered perspective for understanding women's issues in society (Lay & Daley, 2007). Lay and Daley noted that feminist theory centers on comprehending and analyzing how women are oppressed. Because endometriosis affects many women who experience poor treatment in the United States and across the world, feminist theory was appropriate to understand this phenomenon. Also, understanding the extent to which endometriosis impacts women's health, especially their mental well-being, necessitated the assessment of public health concerns from a woman-centered perspective. Feminist theory also allowed the prioritization of affected women's needs and confrontation of gender-based injustices associated with endometriosis, such as delayed diagnosis, misdiagnosis, and improper symptom treatment. Furthermore, feminist theory related to the current study because it is an approach that may foster a better understanding of the impact that endometriosis has on the mental health of women, including Black women. Black feminism assumes a woman-centered view but focuses on understanding what it means to be a Black woman in a society based on racist patriarchy (Johnson, 1983). Other feminist theories ignore how class, race, and gender are interconnected and that there is a sociohistorical context in which these factors must be analyzed (Lay & Daley, 2007).

Black Feminist Theory

Black feminism is a component of feminist theory that focuses on the struggles of Black women (Lay & Daley, 2007). Hooks (1984) pointed out that “the absence of extreme restrictions” (p. 5) results in many women overlooking areas of life in which they are discriminated against or exploited; sometimes, these women may surmise that women are not oppressed. The privileges that non-Black women have might motivate them to be indifferent to the daily racial disparities that Black women and other people of color face.

Hamilton-Mason et al. (2009) explained that the triangulation of socioeconomic status, race, and gender impacts Black women’s psychological health and, in conjunction with other factors, affects their access to health care and behaviors related to treatment. Black women are more prone to poverty than Black men; 30% of Black children under 18 years old are poor; and Black women older than 65 are particularly vulnerable, with approximately 28% living below the poverty line (Hamilton-Mason et al., 2009). Despite these statistics, Hamilton-Mason et al. stated that statistics related to Black women and depression are unclear or do not exist. Hamilton-Mason et al. noted that published work on Black women may be scarce because they might not seek treatment, have been misdiagnosed, are seen as resilient, tend to delegitimize their anguish, or withdraw from treatment due to their cultural needs not being met. Nevertheless, Black women continue to experience oppression while being understudied and undertreated. Black feminist theory implies the intersectionality of race, gender, and socioeconomic status and positions Black women at the epicenter of the complex analysis by bringing to consciousness how they cope with everyday living and the barriers to success (Hamilton-Mason, 2009). A phenomenological design aligned with this theory in that it allowed Black women to tell their stories, including the biopsychosocial and other factors that have impacted their lives and overall wellbeing during the COVID-19 pandemic.

Superwoman Schema or Strong Black Woman Schema

The SBWS is used as a coping mechanism for Black women that arose from their sociohistorical origins that generated the need for various coping styles (Green, 2019). Green stated that although the word “black” is used to describe the women in the SBWS, the term “black” is synonymous with women with ancestries rooted in the history of slavery and being labelled as personal property in the United States. Green explained that Black women live in a sociohistorical context that includes a past of slavery, an oppressive legacy, and gender discrimination compounded by race yielding an inequitable distribution of resources. The SBWS also assumes that Black women face overlapping stereotypical images of themselves and economic issues that have affected their psychological wellbeing. Green asserted that the SBWS comprises three themes related to the psychological health of Black women: caretaking, affect regulation, and self-reliance. Green examined the SBWS as a moderator of the correlation between suicide and depression in Black women and found that depressed Black women using the

SBWS coping style demonstrated an increased risk for suicidality. This finding was most profound concerning the affect regulation factor of the SBWS. This study implied that strength is tied to race and gender for Black women and that strength, an integral component of racial socialization, is a cultural way of handling life’s stressors for Black women. In other words, Black women felt that because they are a woman and are Black, then they must be strong.

Green’s (2019) study highlighted that Black women might mask their pain and are perceived as strong and, consequently, not thought to suffer from suicide and depression. Green discussed that these women are conditioned to wear the mask of strength, decreasing their tendency to seek psychological treatment. Green also pointed out that if medical and mental health care providers have minimal awareness of Black women’s socialization to minimize their pain, deny their vulnerability, inadequately identify their feelings, and adopt a façade of strength, then they will miss the chance to accurately assess Black women’s distress.

Similarly, Watson-Singleton (2017) conducted a study analyzing perceived emotional support as a mediator between psychological distress and the SBWS. The study found that the SBWS was positively correlated with psychological distress and negatively associated with perceived emotional support. This result indicated that Black women experiencing higher levels of the SBWS facets viewed themselves as having less emotional support and experienced higher levels of distress. These findings were relevant across age groups, indicating that this phenomenon might occur in similar studies.

Abrams et al. (2019) produced equivalent results in their study. The authors discussed that “Black superwomen” are at risk for psychological peril and early health decline related to scientific evidence showing that the SBWS construct as a coping mechanism leads to adverse mental and physical health outcomes. The Abrams et al. quantitative study strived to understand how the internalization of the SBWS led to depression in Black women. Their findings suggested that it is overwhelming for Black women to be expected to display strength constantly. The study showed that the more Black women employed SBWS practices, the more prone they were to experiencing depressive symptomology and stress. Moreover, Abrams et al. found that Black women tended to self-silence and externalize self-perceptions to facilitate their dedication to the SBWS ideology and their identity of strength. Lewis et al. (2013) explained this phenomenon further by suggesting that examining the intersection of gender and race requires that self-silencing (i.e., self-perception externalization) is engaged for Black women to cope with gendered racism. Self-silencing was also referenced as a theme of disruption among women with endometriosis in a study by Cole et al. (2021), which will be discussed later in this literature review.

Moreover, Black women are coping with gendered racism while combating harmful, stereotypical, and prejudicial images. The self-sacrificing, mothering, caretaking slave woman stereotype, known as “mammy,” was the harmful origin of the intersectional race- and gender-based discrimination that continues to negatively impact Black women’s health today (Carter & Rossi, 2019). Carter and Rossi stated that Black women had internalized this imagery which manifests in the SBWS. Collins (2005) chronicled oppressive stereotypes (i.e., “mammy” and “superwoman”) and restrictive socio-cultural conditions such as gerrymandering, sexism, racism, and disparities in employment opportunities as creating a cultural climate that motivates Black women’s navigating externalized viewpoints and harmful psychological messages. Black women endure this reality while simultaneously assuming the societal expectation of strength. West (2008) described “Jezebel,” “Sapphire,” and “mammy” as three intersectional gender and racial stereotypes characterizing Black women. Collins (1990) stated that historically Black women have been labelled as docile servants who are angry, controlling Black women, sexually promiscuous women, or non-threatening women. All these roles serve to oppress or marginalize Black women.

Abrams et al. (2019) emphasized that their study captured the societal complexities for Black women regarding intersectionality and how it influenced their psychological wellbeing and everyday existence. Abrams et al. found that the SBWS role prevented Black women from seeking help and identifying what they needed while focusing on projecting an image of control, masking vulnerability. In their study, Abrams et al. found that a large majority (over 80%) of Black women identified as a SBW, indicating that there were possibly many Black women in the United States who needed help but are not seeking treatment because they felt the need to appear strong. Research also found that Black women were underusing mental health services and avoiding self-care (Brown et al., 2010; Ward & Heinrich, 2009). Therefore, Abrams et al. expressed that mental health professionals should learn about these cultural nuances and find ways to introduce mental health to Black women in manners and settings that are culturally comfortable and familiar to them by employing a womanist theoretical perspective.

The womanist theory emphasizes Black women’s need to survive while encouraging balance and healing (Lindsay-Dennis, 2015). Bryant-Davis et al. (2016) stated that womanism is ideal because it concentrates on Black women or women of color, focusing on self-expression and wellness as opposed to victim-blaming. Womanism includes empowerment, embracing multiple identities among Black women, and resistance (King, 2003). Therefore, researchers and practitioners can develop and implement coping mechanisms adapted to womanism, challenging maladaptive coping mechanisms associated with the SBWS. Additionally, clinicians could process stereotypes in treatment to facilitate deconstruction of externalized self-perceptions, allowing Black women to separate their self-image from how others stereotypically view them. Abrams et al. (2019) explained that providers incorporating womanism into counseling for Black women, acknowledging their strength as a positive aspect, could potentially increase the number of Black women who seek psychological care.

Hamilton-Mason et al. (2009) discussed that Black women fulfill multiple roles in their community and family and are consequently seen as strong and not vulnerable. However, despite their strength, Black women still face difficulties related to child-rearing, securing and keeping employment, and taking care of their families while simultaneously being at risk for physical and mental health issues (Hamilton-Mason et al., 2009). Holder et al. (2021) echoed these concerns by discussing that Black women endured job losses due to COVID-19, particularly impacting industries in which Black women are employed in high concentrations. Also, gender- and race-based segregation impacted Black women’s livelihood during COVID-19 (Holder et al., 2021). These findings further supported the rationale for electing Black feminist theory as a foundation for this study.

Biopsychosocial Theory

The biopsychosocial model is an “upgrade” of the biomedical approach. Havelka et al. (2009) explained that the earliest evidence about understanding the relationship between the body and soul, as well as physiology and psychology, dates to 500 to 300 BC in ancient Greece. Hippocrates explored an integrated approach to disease and health care during the stated period, indicating that health relies on correct body fluid proportions. Hippocrates highlighted that this ideology ensures good health when in harmony and causes disease in the cases of disharmony. Havelka et al. mentioned that in early writings, researchers found evidence of a multifactorial disease model stressing the health-influencing roles that extra-organic and natural factors play in disease development. Hippocratic medicine emphasized medicine’s subordination to nature. It focused on controlling patients’ regimens, including exercise, diet, and general life circumstances. However, Hippocrates’ approach differed from later health models, which stressed the vitality of the patient and their behavior and surroundings instead of disease symptoms and features. These approaches, which assumed that various factors impacted health, formed the basis for the contemporary holistic health model. The later health practices indicate that individuals manage their health by employing behavioral forms that preserve wellbeing and treat disease.

Georg Engel, a psychiatry and internal medicine specialist, first championed the implementation of the biopsychosocial model in 1977 when he published it in a science magazine. Engel (1977) explained that the biopsychosocial approach was based on the biomedical model. He asserted that, unlike its predecessor, the biopsychosocial approach to health care supports integrating psychological, social, and biological factors in disease prevention and treatment. Engel indicated that his new model would eliminate the shortcomings of the biomedical approach (Green & Johnson, 2013; Havelka et al., 2009). He explained that the biopsychosocial health care theory could facilitate proper patient diagnosis by collecting holistic patient data, including biomedical and psychosocial information. According to Engel, introducing the biopsychosocial model would maintain biological factors’ role in disease progression and treatment. Instead, the new model expanded upon the previously narrow understanding of health and ailment. In other words, the biopsychosocial approach focused on the sick individual rather than the disease.

Employing the biopsychosocial model in the diagnosis and treatment process motivated the exploration of medical procedures alongside social and psychological restorative efforts. Havelka et al. (2009) expressed that Engel emphasized the biopsychosocial model as beneficial in health care because it promoted teamwork and interprofessional collaboration in practice and research, propelling successful and rapid medical developments. Accordingly, this collaborative health care could benefit Black women who simultaneously endure systemic disparities and endometriosis-related pain or symptomology contributing to mental distress. Havelka et al. stated that the biopsychosocial model is fundamental in research that focuses on psychological stress's impact on somatic disease development. Havelka et al. affirmed the interactions between endocrine, immune, and organic systems in stressful situations. Studies have also shown that strain on system functions or single organs could have indirect consequences that health care providers must consider to maximize treatment effectiveness. For instance, stress can induce risk behavior. Thus, the biopsychosocial model supports the holistic pain theory, indicating that care providers can exploit pharmacological, surgical, and psychological techniques to control pain and alleviate patient suffering.

Additionally, in earlier research, Gatchel et al. (2007) conceptualized a biopsychosocial model related explicitly to pain, concentrating on biological, autonomic, and somatic processes in addition to psychological factors and social contexts. This model would be ideal for aiding medical providers in understanding patients' experiences with pain by examining the multitude of variables that affect them on biological, psychological, and social levels. The below section demonstrates how the biopsychosocial theory has been applied in research settings where women had endometriosis and identified various themes indicating that biopsychosocial factors were relevant in how they viewed their quality of care.

Past endometriosis-related studies have applied the biopsychosocial theory. Friedl et al. (2015) did a cross-section survey study in Austria analyzing the effect of endometriosis on the quality of life, overall psychological health, and occurrence of depression and anxiety in the patient population. The research included 62 patients diagnosed with endometriosis, and the data were collected via standardized health questionnaires: the status of health questionnaire, the endometriosis health profile, and the hospital anxiety and depression scale. The study found that moderate to severe anxiety symptoms were more prevalent and occurred in 29% of the endometriosis patients, while moderate to severe depression was found in 14.5% of the patients; 12.9% experienced both symptoms (Freidl et al., 2015). Freidl et al. acknowledged that endometriosis could result in a decreased health-related quality of life and demonstrated in their study that biopsychosocial factors could impact endometriosis. Conversely, Friedl et al. emphasized that heightened depression and anxiety imply that treatment for psychosomatic disorders is necessary to avert the indication of mental disorders.

Another body of similar research published by Young et al. (2017) sought to describe clinicians' perceptions of the provisions of psychosocial care and the experiences of endometriosis patients. Young et al. indicated that endometriosis patient experiences supported the need for a biopsychosocial approach to treating and managing the disease because the model allowed health care professionals to create individualized care plans for affected women. Young et al. demonstrated that most of the clinicians featured in the study did not qualify themselves as adequately trained to comprehend and offer care for psychosocial endometriosis aspects. Half of the sample population comprising of gynecologists did not believe they needed the training to offer treatment for psychological endometriosis aspects.

Nonetheless, Young et al. (2017) affirmed that since endometriosis is a complex chronic disease associated with psychosocial effects, care options must extend beyond fulfilling patients' biological needs. Young et al. stressed that health care personnel treating endometriosis patients must account for the women's diverse needs. Young et al. explained that, regardless of varying psychosocial care expertise, all health care providers must be capable of determining endometriosis patients' need for psychosocial support. According to Young et al., this idea urged global health care education to integrate the biopsychosocial approach into medical practice. Although the Young et al. study proved relevant to the topic of this study, the doctors were Australian gynecologists. In addition, Young et al. did not account for the role that race plays in forming health care providers' opinions about the experiences of their endometriosis patients. The participants were not Black women, and the study was not done in the United States. These factors confirmed the existence of the research gap that this study was used to fill.

Berterö et al. (2019) conducted a study to describe and identify mutual components characterizing health care encounters between physicians and endometriosis patients. Berterö et al. used secondary data analysis to obtain information from two original face-to-face interviews and a study with 25 participants, including nine endometriosis patients and 16 physicians. Berterö et al. found three themes in their data, one of which highlighted that care continuity formed the base for applying the biopsychosocial approach when treating endometriosis patients. Both the physicians and women featured in the study described the vitality of care continuity. Berterö et al. indicated that they strived for a biopsychosocial care approach, which ensured that the woman was not treated as a biomedical defect object but instead viewed as a component that constitutes a human being. Berterö et al. identified three themes indicative of positive and mutual factors when contacting physicians: continuity as a foundation for a biopsychosocial approach to care; listening sensitively with reflection, thoughtfulness, and responsiveness; and diagnosis timing. Berterö et al. elaborated that the women reported negative experiences associated with physicians’ attitudes related to pain normalization, symptom trivialization, and delayed diagnosis. Notably, Berterö et al. attributed delayed diagnosis or misdiagnosis to endometriosis symptom misinterpretation as menstruation complications.

Likewise, Souza et al. (2011) conducted qualitative research (meta-synthesis of seven qualitative studies of CPP) using the biopsychosocial approach to understand perceptions and the nature of CPP better, especially how it impacted women’s lives who suffer from endometriosis. Souza et al. identified four themes in the study: coping with CPP versus secondary gain, the significance of finding the cause of the pain, doctor-patient relationship expectations, and gender issues. Souza et al. insisted that psychosocial depth must be incorporated into biomedical models, including factors such as motives, attitudes, values, and beliefs that would help understand individuals’ pain and their perceptions about the source and nature of their pain. Given these points, endometriosis patients require medical, psychological, and social care to maximize health outcomes and ensure that women’s concerns are heard, validated, and addressed promptly. Consequently, a biopsychosocial approach is optimum for their care.

Overall, I chose the biopsychosocial approach to comprise the theories that created the framework for this research because it championed a holistic view of the care process. Green and Johnson (2013) explained that the biopsychosocial care model supported the integration of biological, social, and psychological factors in disease treatment. Green and Johnson asserted that the stated model eliminated the shortcomings of the biomedical care approach, assuring better health outcomes. Moreover, as discussed above, Havelka et al. (2009) affirmed that the biopsychosocial health care theory could facilitate proper patient diagnosis through holistic patient data collection.

The biopsychosocial approach was related to the current study because it improves care outcomes when applied in the care of endometriosis patients. This approach helped examine Black women's perceptions of their mental health with endometriosis-related symptoms during the COVID-19 pandemic. It catalyzed a deeper exploration of the psychological, social, and biological factors that impacted their wellbeing. The Black feminist and biopsychosocial approaches supported by an IPA to collect rich and comprehensive data gaining insight into the lived experiences of Black women with endometriosis during the pandemic optimally served to address this study's predetermined qualitative research questions.

Literature Review

The literature review section of this study provides an in-depth discussion of the nature of endometriosis and how this chronic and complex illness adversely impacts women globally. This section starts with a detailed account of Black women's experiences with the U.S. health care system. It then reviews women's experiences with living with endometriosis, the psychosocial impact of endometriosis on women's lives and their relationships (before and during COVID-19), and the limited existing body of research on Black women and endometriosis. The literature review is particularly limited as it pertains to Black women with endometriosis in the United States; this limitation was the primary motivation for this study.

Black Women and Health Care in the United States

Hollingshead et al. (2015) discussed previous research, which found that Black women patients received poor treatment for chronic pain issues compared to male and White patients. Hollingshead et al. did a study to examine the influence of patients' demographic factors on providers' treatment decisions and providers' awareness of these factors influencing their decisions. In the study, 20 medical professionals (10 medical students and 10 medical residents) made virtual decisions consisting of opioid/narcotic pain medication, physical therapy, and antidepressant medication treatment options for 16 patients with chronic pain in their lower back. The medical personnel comprised 65% women (95% non-Hispanic), 70% White, 20% Asian, 5% Black, and 5% Middle Eastern. Hollingshead et al. manipulated the patients' demographic data (race and sex) in their profiles but held the depression status constant. The study showed that 30% of the medical specialist participants were influenced by patients' sex and 15% by patients' race when making decisions resulting in White patients receiving more antidepressant treatment recommendations than Black patients. One trainee stated that economic status influenced their decisions more. Hollingshead et al. mentioned that 50% of the medical personnel indicated that they were aware that the demographic data influenced their decisions. Overall, the findings of this study reinforced findings from previous studies that highlighted Black and women patients being at higher risk for substandard pain management. Existing gaps further complicated the negative impact of this study's research findings on Black women with complex illnesses, such as endometriosis. This deficit in research continues to put Black women at a greater risk of being misunderstood or overlooked, misdiagnosed or undiagnosed, and undertreated.

Bougie et al. (2019) did a meta-analysis of 18 studies to examine evidence indicating the influence of race and ethnicity on the presentation and prevalence of endometriosis. Bougie et al. found that Black women were less prone to receive an endometriosis diagnosis when compared to White women, except in cases of infertility where there was no identified difference. Asian women were significantly diagnosed with endometriosis compared with White women. Also, Bougie et al. revealed that there was no significant difference in the probability of an endometriosis diagnosis between Hispanic and White women. Overall, this study surfaced the existing research gap in analyzing differences in disease presentation among individuals of various ethnic and racial groups. Research has indicated that ethnicity and race may influence endometriosis's severity and clinical presentation due to psychosocial factors influencing pelvic pain symptoms (see Butt & Chesla, 2007; Mathias et al., 1996; Souza et al., 2011). Therefore, race and ethnicity are two factors that must be acknowledged when health care providers treat women who suffer from CPP, pelvic pain, or other symptoms indicative of an endometriosis presentation.

Black people suffer because of unfair treatment resulting in mortality, disability, and morbidity (CDC, 2005; Mays et al., 2007; Mende-Siedlecki et al., 2019). Mende-Siedlecki et al. expressed that grave racial disparities are common in the United States and discussed how Black patients are systemically undertreated and underdiagnosed.

Health disparities had experienced dire consequences that included 60,000 excess deaths of Black Americans between 1979 and 1981, causing the government to consider this situation a national priority (Heckler & U.S. Task Force on Black Minority Health, 1985, as cited in Mend-Siedlecki et al., 2019). These statistics were dated; however, more recent studies confirmed that racial disparities were still ongoing in the United States (Anderson et al., 2009; Bonham, 2001; Cleeland et al., 1997; Hoffman et al., 2016; Mende-Siedlecki et al., 2019; Mossey, 2011; Nelson, 2002; Shavers et al., 2010). Mende-Siedlecke et al. stated that Black Americans were less prone to be prescribed opioids for their pain, less apt to be prescribed pain medication in general, and prescribed lower doses of medication. More specifically, Mende-Siedlecke et al. found that in replicated studies, White providers exercised more strict thresholds for perceiving pain in Black faces when compared to White faces. This research conclusively showed that racial bias in pain management for Black Americans is longstanding and has grave consequences for Black people in this county. Mende-Siedlecki et al. stated that innovative approaches must be developed to fight racial biases at their origins.

Alexander et al. (2019) did a cohort study on 15,136 women who had benign hysterectomies; 25% of the women were Black, and 75% of the women were White. The study found that Black women were likelier to have open hysterectomies than White women. The study also revealed that Black women experienced more major and minor complications than their White counterparts. Alexander et al. expressed that the results remained the same even after the results were adjusted for surgical, medical, and gynecological factors, and offered a possible justification for the outcomes, such as Black women having challenges accessing gynecological care. This study highlighted the need to reduce disparities in surgical procedure direction and post-operational problems that continue to impact Black women adversely.

Jacoby et al. (2010) also discussed ethnic and racial disparities in the prevalence of benign gynecological illnesses resulting in surgical treatments. Jacoby et al. did a review that spotlighted ethnic and racial disparities associated with endometriosis and fibroid tumors, considering the route, rate, and results of hysterectomy. Jacoby et al. mentioned that in a study involving over 500,000 hysterectomy patients, 83% of Black women and 69% of Hispanic women underwent abdominal hysterectomies compared to 62% of White women. Also, Jacoby et al. stated that Black, Hispanic, and Asian women had 40-50% lower chances of having laparoscopic hysterectomies. In the review, Black and Asian women were also more prone to having post-surgical complications than White or Hispanic women. Jacoby et al. also found that Black, Asian, and Hispanic women were less likely to undergo a bilateral salpingo-oophorectomy than White women. This study solidified repeated findings that future research should surround the racial and ethnic disparities in treatment for racial minority women, especially Black women.

The Nature of Endometriosis

As-Sanie et al. (2019) stated that endometriosis is a chronic and painful inflammatory disease that adversely impacts roughly 10% of women and teens worldwide, an estimated 200 million women. However, there is no cure for the disease. Endometriosis causes regular and debilitating, widespread pain, including dyspareunia, dysmenorrhea, infertility, back pain, chronic pelvic pain (CPP), and bowel or bladder problems. As-Sanie et al. stated that pain and infertility were the two most prevalent motivations for women seeking treatment. As-Sanie et al. also mentioned that comorbidities were typical in women with endometriosis. He explained that 95% of women with endometriosis had other mental and physical disorders, such as anxiety, depression, migraines, irritable bowel syndrome, chronic fatigue syndrome, interstitial cystic and painful bladder syndrome, uterine fibroids, ovarian cyst, and fibromyalgia. Also, As-Sanie et al. stated that this painful disease was associated with an increased risk for heart disease; ovarian, breast, and melanoma cancers; and rheumatoid arthritis.

Endometriosis negatively affected psychosocial factors, such as sexual relations, emotional stability, social activities, appetite, sexual relationships, and productivity at work and home (As-Sanie et al., 2019). As-Sanie et al. suggested women lost productivity by averaging 3 hours per week and household productivity by nearly 5 hours per week. Moreover, As-Sanie et al. discussed that endometriosis caused roughly $69.4 billion per year in health care expenses in the United States, with data reflecting that the average annual health care cost was greater than three times higher for women who had endometriosis when compared to women who did not have the disease.

As-Sanie et al. (2019) also identified barriers to diagnosing the disease and stated that societal barriers, stigmas, limitations in understanding the disease, misdiagnosis, and diagnostic delays were vital factors. Continuous barriers to treatment included limitations of existing therapies, challenges in accessing care, the lack of education about CPP and endometriosis, and geographical challenges related to access to obstetrician-gynecologists. As-Sanie et al. explained that although endometriosis was the second leading cause of hysterectomies in the United States, Black women were disproportionately more prone than White women to have a hysterectomy for benign gynecological illnesses and more likely to have surgical complications. These findings indicate that endometriosis puts an unbearable burden on women, their loved ones, and society at large. As-Sanie et al. further explained that advancements in timely diagnoses, positively impactful and effective treatments, and much-needed research and innovation were stagnated by endometriosis-related stigmas and society's persistence in normalizing women's pain. Most importantly, these findings indicate that Black women were being harmed more than their White counterparts. As-Sanie et al. concluded that endometriosis patients' holistic needs must be considered, and a more interdisciplinary and broad approach (along with more intensive and quality research) must be pursued to make strides in women's care.

Women's Perceptions of Living With Endometriosis

Young et al. (2017) qualitatively studied women's perceptions of their experiences living with endometriosis and how they viewed their level of psychosocial care. Young et al. found that the provider's perceptions aligned with the women's reported experiences, especially regarding infertility possibilities. However, the research contained less detailed descriptions of how endometriosis has impacted women's romantic relationships and social and work lives. Young et al. also found that while some clinicians surmised that endometriosis was motivated by mental health deficits, others believed that patients did not require support for the psychosocial needs related to the illness. Young et al. discovered that most practitioners viewed themselves as incompetent in addressing patients’ endometriosis-connected psychosocial needs. Young et al. assessed that while providers had varying levels of expertise, they should have still been able to identify clients’ psychosocial needs to refer them to the appropriate mental health professionals. Young et al. also discussed that some doctors took a more biological approach to treat clients.

Additionally, Young et al. (2017) expressed that some of these medical professionals possibly lacked current and continuing education to better comprehend the psychosocial factors associated with endometriosis, implying that a biopsychosocial approach would have been more appropriate. The study findings indicated a need for more updated clinical guidelines for endometriosis, particularly the psychosocial aspects and targeted care. Young et al. concluded that because there is no biological cure for the chronic disease, treating the related social and psychological challenges may better support women in managing their personal and professional lives.

Morardi et al. (2014) examined women’s perceptions of how endometriosis affected them, examining differences across three age groups from 17 to 53 years old. The study identified two main themes: the experiences of living with endometriosis and the impact of endometriosis on their lives. Morardi et al. discussed that the most prevalent impacts were on physical and psychological factors, social life, and sexual or marital relationships. The study revealed that education, employment and professional opportunities, and fiscal impact were critical issues in women aged 35 years and above. Regardless of the similarities and differences across the age groups, Morardi et al.

indicated that endometriosis negatively impacts multiple daily living factors and often leads to inferior quality of life. Morardi et al. also discussed that women experienced delayed diagnosis, often related to normalizing period pain and that many women did not know much about endometriosis before being diagnosed. The study included findings from 23 quantitative and 16 qualitative endometriosis studies in which a narrative review was conducted. The study identified diagnostic delay, everyday activities and quality of life, childbearing planning, intimate relationships, work and education, self-management, medical management, emotional wellbeing, and mental health as critically impacted categories. Morardi et al. suggested that women and teens with this disease would benefit from including family members and partners in future research and that more exploratory research is needed to understand how endometriosis impacts adolescents. Morardi et al. also stated that research on younger patients could prevent delayed diagnosis and detect the early onset of this chronic disease.

Rea et al. (2020) did a qualitative phenomenological study to explore and understand women’s experiences living with endometriosis. The research included 25 women over 18 years old diagnosed with endometriosis; the average age was roughly 27. The data found that endometriosis impacted the women physically, socially, and psychologically and identified the following four main themes: delayed diagnosis, worsening of one’s life, disastrous intimate life with a partner, and uncertainty about being able to bear children. Rea et al. expressed that challenges related to identifying a cause for the illness influenced patients’ daily lives and that not having a specified reason for the symptomology created the perception of non-healing and the absence of a targeted treatment. The absence of a diagnosis impacted their social life, and the participants described feeling isolated and having negative emotions and feelings due to their situation being misunderstood.

Rea et al. (2020) expressed that women made statements such as, "... in the end that was at the point of giving up"; "I had been told that I was unlucky, a painful menstrual cycle, with abdominal repercussions and other pains that were all probably related to that period"; "... no one seemed to believe me. I felt isolated and angry ... nobody believed me, but then the diagnosis arrived"; and "for a long time I felt like I was alone, nobody believed me ... but I really felt so bad and it couldn't have been physiological or just psychological ... I was really sick, my body was saying so, but I was the only one who was listening to it" (p. 4). Regarding the worsening of women's lives, Rea et al. reported that endometriosis and its related symptoms, such as persistent pain, harmed their overall quality of life prior to diagnosis. Rea et al. stated that the women in the study demonstrated that they had "painful lives" (p.4) and described how pain has completely influenced their existence. Participants reported that the disease affected daily activities, including work performance, social relationships, and time management. Rea et al. mentioned that women stated things such as, "my performance at work has also decreased ... I sometimes skipped work inventing a thousand excuses" and "I started going out less even with my friends ... and they didn't always understand ... they thought I was exaggerating or who knows what else" (p.4). Rea et al. explained that women also reported feeling guilty about not being able to do chores and relax, leading to feeling "exhausted and irritable" (p. 4) the next day.

Rea et al. (2020) discussed another emerging theme related to damaged intimate relationships with significant others. Women explained that they feared the upset of their intimate life would negatively influence all aspects of their marriage or intimate relationship. Rea et al. elaborated that women made statements such as, “I always end up refusing even though I actually want to be with him”; “it’s unpleasant and unfortunately it has barriers, walls between us … it’s hard to get him to believe me”; “my sex life was deeply affected ... the pleasure has almost completely disappeared”; “different positions don’t change those unpleasant sensations ... “; and “my sex life is almost over, I continually avoid my husband and sometimes fear betrayals or even divorce” (pp. 4-5).

The last theme that surfaced was related to women’s uncertainty about being able to have children, which Rea et al. (2020) stated was inherent to being a woman and culturally considered a fundamental component of womanhood. Women in the study expressed concerns related to being able to complete a pregnancy as well as the fetus’ health being affected by their treatment for endometriosis. Women made statements such as, “the fear of not being able to have children destroys me ... it’s a thought that unfortunately impacts daily life and tends to isolate me because other people don’t understand, wouldn’t understand” and (on pondering whether or not she could have children) “I was already feeling down, then that thought broke me completely” (p. 5). Rea et al. also stated that women reported that they must live with endometriosis-related problems while simultaneously being “super” (p. 6) in their roles as mothers, wives, and workers. This study demonstrated how endometriosis is an incurable disease frequently diagnosed late and remarkably disabling for its sufferers, imposing tremendous strains on their intimate, family, personal, and professional lives. Furthermore, Rea et al. indicated that the fear of the disease, and its association with the inability to have children and sustain a healthy intimate relationship, justifies providing women diagnosed with endometriosis with psychological support through targeted interventions.

Fauconnier et al. (2013) did a qualitative phenomenological interview-based study comparing physicians' and patients' descriptions of endometriosis symptoms, including 41 women diagnosed with various kinds of endometriosis and nine gynecological surgeons. Forty-seven themes were identified in the study. Clinicians and patients perceived 30, patients perceived 12, and clinicians perceived five. The themes fell into five categories identified by participants and consultants as follows: (a) pelvic pain and dysmenorrhea, (b) dyspareunia, (c) gastrointestinal symptoms, (d) bladder symptoms, and (e) other symptoms. The twelve symptoms that the interviewed women reported were paralyzing, handicapping pain affecting mobility; continuous pain with attacks of more intense pain; ovarian pain; pain lasting longer than menstrual pain continuing after bleeding stops; pain before, during, and after menstruation; stabbing pain; prickly pain; lower abdominal burning pain; pain preventing sleep and waking up at night; pain that spreads to the legs and hips; burning feeling during or after sexual intercourse; and dizziness or fainting. These findings highlighted that clinicians' descriptions of severe pelvic pain were incomplete compared to the patients' descriptions, suggesting that they accurately understood the illness' severity and complexity. Other findings suggested that women with endometriosis considered dysmenorrhea and other pelvic pain on a spectrum and did not differentiate between the two types of pain. Fauconnier et al. revealed the importance of using open interviews instead of questionnaires in research of this nature because they allowed subjects to detail their perceived experiences in their own words, which could (in turn) be used to develop questionnaires to diagnose women with endometriosis. This critical finding had implications regarding health care providers understanding the complexity and severity of their patient’s symptoms and making a timely and accurate diagnosis.

Namazi et al. (2021) conducted a qualitative study of 20 married patients aged 23 to 43 years with endometriosis in which they conducted semistructured interviews. The study found comparable results to the Rea et al. (2020) study. Namazi et al. analyzed data that resulted in five categories: physical suffering, mental disorder, instability of marital life, disruption in social life, and self-care. The study showed that endometriosis could negatively impact women’s lives physically, psychologically, socially, and sexually. Namazi et al. stated that the participants reported severe hemorrhaging, clotting, and spotting before and after their irregular menstruation cycles. Namazi et al. also reported that the participants’ pain was intense and unbearable. Sub-themes identified in the study included menstrual disorders, crippling pelvic pain, sexual dissatisfaction, emotional tension with spouses, frustration, repeated failure feelings, self-condemnation, disruption in daily activities, isolation, altered lifestyles, and pain management. One participant stated, “my pain was so terrible, I did not like to be alive ... It was so hard to breathe, I wanted to die” (p. 1278). Other comments included, “I feel my ovary is exploding. I can’t do anything, I just cry”; “My pain starts from the middle of my stomach, then it spreads around my abdomen and my lower back and legs”; “I constantly say to my husband that we should be separated ... “; “It’s so annoying that I have no desire for intercourse at all”; “During intercourse, I have pain so much that I never enjoy it”; “I’ve done hysteroscopy twice, IUI (intrauterine insemination) several times, and IVF (in vitro fertilization) twice, but none of them was successful”; and “I have undergone surgery for several times, but my illness is recurring” (pp. 1278-1279). The findings in this study reinforced the findings in earlier studies. Namazi et al. surfaced the underresearched nature of endometriosis and the dire mental, emotional, and physical consequences that its sufferers and their families endured.

Drabble et al. (2020) did qualitative semistructured interviews with 20 women that found that endometriosis pain affected multiple parts of women’s bodies, including their bladder, bowel, kidneys, lungs, upper body, nerves, lower limbs, and head. Drabble et al. referred to the types, patterns, and intensities of pain as the constellations of pain. The findings in the study implied that the diversity and complexity of women’s pain had projections for improving their diagnosis and non-medical and medical pain management and enhancing the clinical experience with providers. This research recapitulated that understanding the breadth and depth of endometriosis pain contributes to earlier diagnosis and identification of effective strategies for meaningfully addressing its symptoms.

Facchin et al. (2018) did a study to develop a grounded theory regarding the impact of endometriosis on mental health. Facchin et al. conducted open interviews on 74 women aged 24 to 50 years in which four categories surfaced: (a) experiencing pain, (b) having a chronic disease, (c) dealing with anticipated or ascertained infertility, and (d) needing specialized and multidisciplinary care. The primary struggle for all the women in the study was that endometriosis is incurable. Furthermore, the study found that nearly all the participants expressed symptom onset, including intense pelvic pain. One participant said that her pain included her rectum, legs, back, and head and "... drives you crazy" (p. 6). Like other studies (see As-Sanie et al., 2019; Morardi et al., 2014), participants expressed that their doctors misunderstood their health issues, which normalized their pain. Facchin et al. explained that this normalization of the women's pain frequently led to delayed diagnosis and, consequently, delayed treatment causing them to feel severe physical and emotional suffering described as "panic" and "terror," (p. 9) harmful hospital admissions, and dark experiences with providers.

The findings discussed above segue into the most critical results of the study related to how endometriosis affected the participants' mental health. Facchin et al. (2018) reviewed the differences between distressed and non-distressed women, comparing experienced disruptions and restored continuity at the core of their grounded theory. Facchin et al. defined *disruption* as an endometriosis-related interruption in women's daily lives. Distressed participants expressed that they experienced acute disruptions in five core areas of their lives every day. Facchin et al. mentioned that the women felt severely overwhelmed or even conquered by the disease to the extent of living their lives around its existence. The study identified six factors for the "experiencing disruption vs restoring continuity" process as follows: (a) pathway to diagnosis (communication of diagnosis), (b) quality of the doctor-patient relationship, (c) current presence of symptoms, (d) support (intimate relationships and financial support),

(e) female identity (impact of infertility, body image, and sexuality), and (f) meaning of life with endometriosis.

Facchin et al. (2018) explained that all women discussed their journeys regarding the pathway to their diagnosis. As mentioned above, distressed women reported that it took them up to 12 years from symptom onset to receive a diagnosis, reporting doctors' normalization of their symptoms as the culprit. After being diagnosed, these women reported feeling like their pain was validated. However, the women reported that the way their diagnosis was communicated included poor information and lacked empathy, making them feel fearful, lonely, helpless, and out of control. On the other hand, non-distressed women (who reported the lowest anxiety levels) reported communications with their doctors as being "transparent," "clear," and "open" (p. 10). Regarding doctor-patient relationships, distressed women reported feeling distrustful of their doctors and expressed strained relationships and intense anger related to their pain not being validated and inappropriate diagnoses. On the contrary, non-distressed women reported having positive relationships and feelings with their providers and mentioned words like "empathy," "competence," and "understanding" (p. 10). The non-distressed women felt understood, supported, and validated, and several embraced being included in clinical trials and expressed their belief in clinical research.

On the theme of the current symptoms, Facchin et al. (2018) reported that the distressed women suffering from chronic pain expressed that they were not on hormonal therapy and had other physical conditions (i.e., chronic fatigue, Crohn's disease, and other illnesses). Unlike their non-distressed counterparts, the distressed participants had not effectively discovered a way to manage their endometriosis-related symptoms. Regarding support, distressed women felt alone in multiple relationships while trying to cope with endometriosis as opposed to non-distressed women who felt “supported,” “sustained,” “accompanied,” and “loved” (p. 11) providers and their significant others. Facchin et al. stated that distressed women reported negative emotions towards their partners and felt guilty, angry, and ashamed.

Facchin et al. (2018) stated that the women reported that their need for financial support motivated feelings of stress. The study revealed that endometriosis affected the distressed women’s female identity causing mental strain. Distressed women also struggled with issues related to infertility. The women expressed challenges with feeling frustrated due to the inability to get pregnant, pressures for untimely pregnancy from providers, and related mental disorders (anxiety disorders with panic attacks and moderate to severe depression). Also, few of the distressed women sought psychological support. Although female identity issues related to body image affected almost all the women in the study, distressed women expressed issues with wanting to hide their bodies. The women also mentioned other issues, such as the constant desire to control weight gain, poor libido, hot flashes, vaginal dryness, and tiredness. Lastly, concerning the meaning of life with endometriosis, distressed women felt that their identity was defined by endometriosis and that they would fail as women, feeling convicted as females. On the other hand, non-distressed women identified growth despite their endometriosis diagnosis, experienced pleasantness and positivity, and were not defined by their disease.

Facchin et al. (2018) demonstrated the critical nature of disruption in women with endometriosis and how disruption resulted in distress. The study emphasized that non-distressed women adapted better to disruptions and were better able to restore continuity in their lives, resulting in lower stress levels. Facchin et al. cited multiple reasons that women could have been more resilient concerning disruptions related to endometriosis (i.e., personality, family and financial support, positive relationships, and competent doctors). Subsequently, Facchin et al. showed the importance of endometriosis patients receiving integrated care between gynecologists and psychologists and caregivers providing timely and accurate information and diagnosis. An underlying but significant factor of this study was that a positive doctor-patient relationship based on transparency, trust, and validation of patients' pain and experiences, could have mitigated the degree of distress that patients endured.

Pettersson and Berterö (2020) did a qualitative literature review analysis of 14 studies, including 370 women diagnosed with endometriosis revealing that women felt they were met with incompetence when receiving non-specialized care. The findings aligned with those found in the Facchin et al. (2018) study; the women experienced delayed diagnosis and treatment. Pettersson and Berterö mentioned that the women also believed their providers did not take their symptoms seriously. The women in the study expressed feeling frustrated, anxious, vulnerable, and invalidated. The women also repeatedly mentioned having challenges trying to convince doctors that their symptoms were not solely attributed to menstrual pain and bleeding. The Pettersson and Berterö study highlighted the need for women with endometriosis to receive support from specialized and competent health care professionals to manage their lives. Similar to this study, Grundstrom et al. (2018) conducted a study which found that health care encounters were viewed as a double-edged experience by endometriosis patients: destructive (characterized by invalidation, exposure, and ignorance) or constructive (marked by acknowledgement, visibility, and confirmation/self-esteem enhancing).

Cole et al. (2021) did a qualitative study including 34 women via an online survey examining how women change their identity to adapt to living with endometriosis within an environment that minimizes and delegitimizes their symptoms and promotes conformity to female gender role norms. Notably, this was the only study including Black women not researching endometriosis in the African population, expressing that one of the participants self-reported as multi-ethnic (Black Caribbean) and another as Black/Black British (African). The study revealed that all women felt that endometriosis was responsible for disruptions in their identities, described as biographical disruptions, and identified four themes: (a) not feeling like themselves, (b) reactions from social and medical individuals motivated feelings as if they were going “mad,” (c) feeling like a burden to loved ones (which resulted in the fourth theme), and (d) self-silencing.

The definition of disruption in the Cole et al. (2021) study was similar to that described by Facchin et al. (2018) in their study. Cole et al. explained that the women in the study disclosed not feeling like normal women and feeling distressed because they were challenged by trying to maintain their feminine identity while having infertility concerns and shameful personal symptoms. The women discussed their inability to receive proper treatment for their symptoms due to (what they perceived as) being “cast as the hysterical woman" (p. 186) by their providers, which resulted in the women second-guessing their sanity. The women also described frustrations (and immediate relief) with the delayed validation of their symptoms and how the diagnosis impacted their identity, including self-silencing, which proved harmful and contraindicative to self-care and the healthy reconstruction of the women's identities. Cole et al. explained that participants reported that they managed their feelings of guilt and dismissal of their symptoms by dealing with their symptoms alone. This theme recalled the title of the article reflecting a quote from a participant, Nadia, who described endometriosis as "the most lonely condition that I can imagine" (p. 184).

This study supported other research findings regarding guilt, symptom invalidation, and frustrations with delayed diagnosis (see Facchin et al., 2018; Moradi et al., 2014; Rea et al., 2020). Although this study repeated themes established in research studies on women with endometriosis, it also highlighted how endometriosis can cause women to self-isolate, neglect their feelings, suppress their pain, and deny their need for proper self-care and physical and mental health attention.

Endometriosis, Multimorbidity, and Psychological Distress

Geller et al. (2021) did a study to construct a model on the effect of endometriosis on psychological distress in women with the disease. The role that body image, self-criticism, and pain intensity played on psychological distress related to endometriosis and the impact that chronic sickness had on distress development were analyzed in the study. The study had 247 women participants aged 20 to 49 years; 73 had endometriosis, 62 had endometriosis and other chronic diseases, and 112 were healthy. Geller et al.

demonstrated elevated anxiety and depression levels in women with endometriosis compared to their healthy peers. Moreover, the study found that depression was higher in women with endometriosis and an additional chronic illness than in those with endometriosis only. Results showed that depression and anxiety were mediated by body image when comparing the healthy group and endometriosis group with another chronic illness. Depression was mediated by pain intensity, body image, and self-criticism when comparing the endometriosis group and endometriosis group with an additional chronic illness.

The Geller et al. (2021) study also found that women with endometriosis and an additional chronic illness experienced poorer body image and more self-criticism than healthy women, resulting in heightened psychological distress. Geller et al. assessed that these women's elevated distress was possibly motivated by their self-judgement and belief that their ill bodies would never measure up to society's beauty standards, which led to a cycle of more self-judgement and body shame. Geller et al. mentioned repeated themes regarding women with endometriosis being impacted by COVID-19, such as self-isolation and its damaging psychological effects and limited access to health care and surgical appointments; the writers attributed these burdens to these women's added distress.

The Geller et al. (2021) study emphasized the importance of health care professionals focusing on women with endometriosis and multimorbidity. This group of women required special attention because they were more susceptible to higher levels of psychological distress, which may have been enhanced by concerns about pain intensity, body image, and negative self-judgement. Geller et al. found that COVID-19 restrictions further complicated these issues.

Impact of Endometriosis on Sleep

Facchin et al. (2021) examined the relationships between pelvic pain, fatigue, endometriosis, and sleep. Facchin et al. primarily examined sleep disruptions and fatigue in women with endometriosis (compared to those without endometriosis), concentrating on the role of pelvic pain. The study considered the quality of life and psychological wellbeing in endometriosis patients, including analyzing good versus bad sleep quality. Facchin et al. found that endometriosis impacted sleep and fatigue, showing that women with pelvic pain experienced sleep disturbances, more significant fatigue, more daytime sleepiness, poor sleep quality, and more chronic insomnia than women without pelvic pain symptoms. Over half (56%) of the patients reported having fatigue frequently, and 67% of patients with pain symptoms experienced regular bad sleep quality.

The results of this study by Facchin et al. (2021) demonstrated the interrelated and cyclical nature of sleep disorder, chronic pain, and psychological symptomatology (namely depression and anxiety). Overall, the findings in the study indicated that psychological care for women with endometriosis should include a sleep hygiene assessment. Facchin et al. also stressed acknowledging how CPP contributed to sleep disruptions and, in turn, impaired patients’ quality of life and psychological wellbeing.

Impact of Endometriosis on Relationships

Pereira et al. (2021) did a couple’s study on the impact of psychological morbidity on women with endometriosis, considering the duration of the couple’s relationship and the disease, including whether the women’s satisfaction with sex affected their psychological morbidity. The study, which included 105 women and their partners, demonstrated a direct effect between women’s psychological morbidity and marital satiation and symptom severity. The study also revealed that infertility and sexual activity indirectly affected the correlation between sexual satisfaction, the duration of the diagnosis, and psychological morbidity. Lastly, the study showed that sexual satisfaction in the women directly affected their partner’s marital gratification, prognosticating reduced psychological morbidity in both the woman and her partner. Pereira et al. thoroughly reviewed the nature of how endometriosis impacted women and their partners. This study supported previous studies regarding endometriosis being mentally and physically debilitating, a negative burden on intimate relationships, an imposition on social and daily activities, and a barrier to childbearing (see Agarwal et al., 2019; Golfier et al., 2018).

Pereira et al. (2021) also reviewed how this chronic illness adversely affected psychological functioning, causing depression and anxiety symptomatology which can be exacerbated by CPP. Pereira et al. mentioned that women with endometriosis also suffered from dyspareunia and CPP leading to high depression and anxiety levels, which illustrated the significance of taking into account the severity of endometriosis symptoms when considering how it impacted psychological wellbeing (see Facchin et al., 2015; Lagana et al., 2017). The study revealed that 92% of women’s partners (of the women with endometriosis) reported negative feelings regarding the impact of the illness on their lives. Partners also demonstrated high anxiety and depression (see Ameratunga et al., 2017; Culley et al., 2017; Pereira et al., 2021) in addition to feelings of worry, anger, frustration, and helplessness (see Culley et al., 2017; Pereira et al., 2021).

The overall results of the Pereira et al. (2021) study and other similar studies underscored that health care interventions should have considered reported symptom severity and sexual and marital satisfaction to decrease psychological morbidity in women with endometriosis. Marital satisfaction was also discussed as a critical key for women with endometriosis and their partners in mitigating harmful psychological comorbidities. Pereira et al. found that the partners' sexual satisfaction was affected by the women's sexual contentment. Therefore, this study clearly illustrated the benefit of assessing couples together when the degree of psychological morbidity and symptom severity associated with endometriosis and marital and sexual satisfaction are determined.

Butt and Chesla (2007) conducted an interpretive design with a narrative investigation of women's and their partners' understanding of endometriosis, symptomatology experiences, and responses to living with endometriosis-related CPP. Butt and Chesla explained that CPP is a chronic pain condition that affects 26% of women and accounts for 12% of hysterectomies and 40% of laparoscopies in the United States. Germane to the Butt and Chesla study and this body of literature, Lamvu et al. (2021) expressed that CPP is comparable to other chronic pain syndromes because biopsychosocial factors influence and contribute to pain.

Butt and Chesla (2007) discussed that CPP etiologies included endometriosis (the most common diagnosis of CPP), pelvic inflammatory disease, bowel- and bladder-related pain, adhesions, nerve-related pain, and musculoskeletal pain. Treatments for endometriosis-related CPP included medical and surgical therapy. However, surgical therapy often involved adhesion separation (scar tissue), cyst removal, and destruction of endometriotic tissue. Hysterectomy and bilateral salpingo-oophorectomy were other suggestions to remedy the pain (see Butt & Chesla, 2007; Kramer & Reiter, 1997). The medical therapy for endometriosis-related CPP was hormonal treatment. Butt and Chesla mentioned that research had demonstrated that 80% of women with CPP had disruptive levels of distress leading to work absences due to pain. Over a third of these women consumed analgesics daily to temper their pain, and nearly one-third experienced reduced social functioning, lowered energy levels, and mental health challenges (see Butt & Chesla, 2007; Mathias et al., 1996; Stones et al., 2000). Research has also shown that women with CPP were more prone to be divorced, separated, or widowed than single (see Butt & Chesla, 2007; Mathias et al., 1996). Other research has shown various sexual functioning challenges related to CPP, such as statistics demonstrating that up to 75% of women with CPP also had dyspareunia (see Butt & Chesla, 2007; Collett et al., 1998; Selfe et al., 1998).

Overall, Butt and Chesla (2007) found that couples living with CPP related to endometriosis viewed the experience as emotionally and physically painful and symptoms as disruptions in daily life and intimate relationships. One main issue was that couples had trouble understanding the symptoms and securing adequate treatment. Butt and Chesla also pointed out that pelvic pain was unpredictable and disabling. A third issue was that shortly after couples learned of a diagnosis, they learned that there was no definitive cure for the disease; even after hysterectomies, problems surfaced. Butt and

Chesla explained that couples in the study experienced profound grief and identified five subjects which indicated the degree of couples' entanglement as follows:

- together but alone
- battling endometriosis together
- conjoined through disability
- totalized by caregiving
- engaged in mutual care

These findings indicated the need for more longitudinal studies to understand better how relationship patterns for these couples evolved.

Impact of COVID-19 on the Mental and Physical Health of Women with Endometriosis

Search results indicated that 12 peer-reviewed studies addressed women with endometriosis during COVID-19. Of the 12 studies I initially found, two were done in the United States, and only one included a Black woman. Three studies were done in Australia, and single studies were done in Puerto Rico, the Netherlands, Germany, London, Brazil, Italy, and Iran. This section reviews the findings of these studies. However, other peer-reviewed studies may have been published since this study was completed.

Evans et al. (2021) did a longitudinal study in Australia of 162 women with dysmenorrhea and endometriosis to understand how COVID-19 had impacted women with endometriosis. Evans et al. found that the women experienced similar disruptions and positive feelings related to working from home as the community at large. However, 60% of the women reported that the pandemic impacted their health care needs because of cancellations and delays in treatment, telehealth matters, and other COVID-19 restrictions. Evans et al. explained that while 23% of the women with COVID-19 reported an adverse impact on their symptoms (namely stress), 76% reported that the pandemic impacted their daily functioning. The women in the study also demonstrated clinically elevated levels of fear related to the pandemic. Evans et al. emphasized the issues that women experienced prior to the pandemic, such as delayed care due to waiting lists. The study addressed the importance of women with endometriosis practicing self-efficacy and self-care instead of relying on health care professionals. Evans et al. also emphasized the benefits of allowing people with endometriosis to work from home post-COVID. Evans et al. proposed premium telehealth services, distribution of evidence-supported health care strategies, and prompt return to in-person care to reduce patients' COVID-19-related fears.

Ramos-Echevarria et al. (2021) did a cross-sectional study in Puerto Rico on 82 women to determine if practices to reduce COVID-19 infections significantly impacted endometriosis symptoms, stress, health care access, and risk behaviors. Six themes were identified in the study: (a) mental health (anxiety, panic attack, depression, and sleep disruptions), (b) endometriosis and menstrual cycle symptoms (dysmenorrhea, amenorrhea, and dyspareunia), (c) access to medical care (treatment and medical consultation), (d) impact on lifestyle (work/finances, social support, and coping), (e) positive impact (self-awareness), and (f) no impact. Findings indicated that the women's endometriosis symptoms were exacerbated. The women had elevated levels of peritraumatic stress during the pandemic; nearly 76% of the participants reported pandemic-related stress. The women also reported that their risk behaviors changed concerning their behaviors before the pandemic. Seventy-two percent of the women reported that their jobs were affected (17.3% lost their job), 40% of the women reported decreased exercise time, and 70% of the women reported that they had food insecurity; 29.2% reported increasing their alcohol consumption.

Ramos-Echevarria et al. (2021) stated that the women reported that the primary symptoms that worsened during COVID-19 were back pain, fatigue, and headaches. Although telehealth and other electronic health applications were adequate for the women, they expressed having challenges in receiving medical care, including difficulties scheduling appointments and obtaining prescribed medications. Ramos-Echevarria et al. explained that 44% of the women reported provider-canceled or delayed appointments; one-fourth of these women cancelled their appointments due to the fear of contracting COVID-19. The study found that COVID-19 adversely impacted women’s overall health and wellbeing and concurrently restricted their access to timely health care.

The findings in the Ramos-Echevarria et al. (2021) study heralded the need for more long-term studies to be developed that strategically address the harmful effects of pandemics and other natural disasters on women with endometriosis. This topic is particularly critical because many women with endometriosis in the study experienced health care challenges prior to the pandemic, which caused them distress; the pandemic only increased their distress.

Rosielle et al. (2021) conducted a study in the Netherlands using questionnaires completed by 330 infertility patients, 181 endometriosis patients, and 101 health care professionals to assess the impact of COVID-19 on this population. The study echoed the findings of Ramos-Echevarria et al. (2021) regarding women with endometriosis considering telemedicine as a viable alternative during the pandemic. However, Rosielle et al. stressed that telehealth was no substitute for physical consultations. The study found that 80% of the health care specialists, 75.9% of the infertility participants, and 64.8% of the endometriosis patients rated telephone appointments as a suitable alternative for in-person consultations during the COVID-19 lockdown. The findings also indicated that the quality of life for infertility patients decreased during the pandemic. This population expressed increased stress levels and the inability to cope with changes to their health care due to COVID-19 restrictions. This study revealed the gap in research related to virtual care's effectiveness in future pandemics or other natural disasters.

Schwab et al. (2021) did a study in Germany. This study examined how social distancing practices during the pandemic lockdown affected women's perception of pain in patients with chronic pain related to endometriosis. Schwab et al. assessed the effect of social isolation on pain perception, pain intensity, and social support. The study included 258 participants and found that dysmenorrhea, the symptom associated with the highest pain level, decreased substantially during COVID-19. The findings indicated that social distancing contributed to the improvement of pain-induced disability in most participants. The pain was negatively impacted by social distancing due to the heightened awareness (or hypervigilance) of pain frequency. This recent body of research helped bring awareness to the disruptions to social and medical support that ill-prepared health care systems perpetuated during the pandemic. It also surfaced a potentially unintended benefit for women with endometriosis regarding social distancing and how it contributed to their increased self-awareness and reduced pain.

Rowe and Quinlivan (2020) conducted a study in Australia that analyzed how having infertility issues and endometriosis increased anxiety due to social restrictions, economic issues, and fears related to COVID-19. Their article reflected on the harmful nature of patients with endometriosis and infertility complications not having their needs addressed. Rowe and Quinlivan articulated that these diagnoses carry a high economic costs and are associated with stigmas, reduced social involvement, and mental distress that often co-occur. The disease was labelled a “contested disease” due to its elusive nature and the lack of consensus for its cause, treatment, progression, and existence. Rowe and Quinlivan suggested that infertility and endometriosis be addressed with counseling and symptom management to support women who still cope with the hardships associated with their chronic illness that persisted despite COVID-19 limitations and priority diversions.

Demetriou et al. (2021) did global surveys in Europe, Oceania, North America, Latin America, and the Caribbean to explore how COVID-19 affected women with endometriosis. Out of the 6,729 women respondents, over half of them reported concerns that endometriosis made them vulnerable to COVID-19. Moreover, 5,428 women (80.7%) of the respondents reported that COVID-19 impacted their care negatively in at least one way; the results were similar globally. The study also showed that 20.3% of the respondents had challenges accessing their medication, 50% postponed or cancelled gynecology appointments, and 37.2% postponed or cancelled their medical procedures. Some women explained that they had to change or stop a medication, while others had challenges securing refills. Demetriou et al. stated that the women expressed their top three priorities during the pandemic: connecting with their gynecologists, awareness of procedural appointments, and psychological care. This study stressed that understanding what health care factors are important to this population of women was essential for developing and prioritizing their support services during times like the pandemic.

Crispi et al. (2021) examined endometriosis elective (minimally invasive) surgeries in Brazil during the first wave of COVID-19 through an observational study of cases for 11 women. Crispi et al. aimed to examine the safety of surgeries on women with endometriosis and monitor them for COVID-19-related symptoms post-operation. The study resulted in none of the participants contracting COVID-19 symptoms, such as dyspnea, fever, or cough, in the 40 days of postoperative checkups. Crispi et al. demonstrated that endometriosis-related procedures could be safely performed during a pandemic. However, Crispi et al. emphasized that patients with COVID-19 should have procedures only when necessary and that their surgeries should be performed in a safe environment. This study was valuable because it is evidence-based research that may have been used to reassure women with endometriosis who critically needed surgery that their procedures could be conducted safely during a pandemic.

In Italy, Arena et al. (2021) administered an extensive cross-sectional online survey to 468 women to analyze the effect of COVID-19 on women with endometriosis quantitatively. The study found that the pandemic significantly affected women’s lives who had the illness and demonstrated that 68.8% of the participants were worried (to varying degrees) about the inability to access gynecological care. Arena et al. stated that higher levels of anxiety, older age (women over 40 years old), and unemployment independently correlated with increased post-traumatic stress disorder (PTSD) onset risks. Arena et al. attributed older women’s proneness to higher incidences of PTSD to their having experienced painful suffering for a more extended period (as opposed to younger patients who generally have more recent diagnoses). Arena et al. elaborated that 75.6% of the women viewed telemedicine favorably and insisted that the implementation of telemedicine (i.e., phone and video appointments) in routine care presented a viable and acceptable solution for reducing patients’ feelings related to isolation and unmet health needs. This study built upon other studies, such as that done by Rosielle et al. (2021), that determined telemedicine as an acceptable mode of treatment.

Moazzami et al. (2021) did a controlled study in Iran, comparing 507 women with endometriosis (case group) to 520 without endometriosis (control group) to measure factors related to the susceptibility to COVID-19 infections in women with endometriosis. Variables compared between the two groups included H1N1 infection, COVID-19 infection, H1N1 vaccine, travel, social distancing, close contact, symptoms, screening, admission, and isolation. The symptom categories were none, fever, sore throat, nasal congestion, cough, shortness of breath, headache, weakness and muscle pain, reduced sense of smell or taste, ocular problems, and others; the other variables had yes or no responses. The study found that women with endometriosis had a higher frequency of gastrointestinal, hematologic, dermatologic, and neuronal disorders but a lower occurrence of febrile and asymptomatic infection. Findings demonstrated that close contact with a COVID-19-infected patient was the only risk factor identified in both groups resulting in a slightly elevated chance of infection. Overall, the study's results implied that having endometriosis does not increase the chances of being infected with the COVID-19 virus. However, the study also implied that the public must contemplate protective measures to reduce contracting and spreading of the virus and mitigate sustaining the pandemic climate.

In the United States, Gupta et al. (2021) analyzed how COVID-19 affected gynecological surgeries. The study was a retrospective study for all patients having gynecological surgeries in a large academic hospital from March 16, 2019, to July 31, 2019, and from March 16, 2020, to July 31, 2020. The study was divided into three periods: In period one, there were no nonessential procedures performed; in period two, urgent procedures were performed; and in period three, complete surgical procedures resumed. Overall, the study found a 73.6% decrease in cases over period one, a 20.1% reduction in procedures during period two, and a 2.9% increase throughout period three. Although this study did not solely address the impact that COVID-19 had on endometriosis surgeries, one notable finding related to endometriosis procedures was that in 2020 (during period two), endometriosis and uterine fibroid surgeries accounted for the most significant reduction in procedural volume.

The most significant finding of endometriosis procedures was that from 2019 to 2020 (during period one), resection of endometriosis decreased by 90.4%. Gupta et al.

(2021) emphasized that benign gynecological surgeries, such as those for endometriosis, were delayed unequally during period one and that surgery for fibroids and endometriosis was impacted the most. The adverse effects of not having nonurgent surgeries for these conditions (which are considered benign) could have had dire consequences for patients, such as hospital admissions, periodic emergency room visits, and the continuation of CPP, hemorrhaging, and other physical and psychological manifestations. This study was valuable because it expressed the need for institutional or administrative decisions regarding determining which gynecological surgeries are priorities, including surgeries for benign conditions. It also recognized the need to revisit future policies based on individual patient experiences, which can enable better-informed decisions.

Movilla et al. (2021) briefly described a case in the United States where a surgical intervention was performed on a patient because of ineffective medical management, despite the cancellation of scheduled elective surgeries at the facility. Movilla et al. used the case to briefly demonstrate that not all endometriosis surgeries can be considered elective, especially in critical cases where medical treatment fails and complex conditions involving severely invasive endometriosis with colorectal entanglement surface. This case supported the message that Gupta et al. (2021) articulated regarding the potentially harmful effects of delaying elective surgeries. It illustrated the importance of considering individual patient situations instead of labeling all endometriosis-related surgeries as elective or benign.

Black Women and Endometriosis

Roughly five existing studies specifically addressed endometriosis among Indigenous African women. I found two studies that included African American women. Wanyoike et al. (2017) reviewed four papers to examine the clinical presentation and diagnosis of endometriosis in Indigenous African women. The study found that endometriosis prevalence ranged from 0.2% to 48.1%, considering hysterectomy and laparotomy specimens.

Kyama et al. (2004) pointed out that although endometriosis was discovered as a disease in 1927, there was still a void addressing its prevalence in Black women. Kyama et al. indicated that the mindset in the medical community was that endometriosis was rare in women of African origin. Kyama et al. also mentioned that research indicated that endometriosis among African American women was more commonly detected in private hospitals than in public hospitals. Kyama et al. stated that research supported that endometriosis prevalence in African-Indigenous women with infertility problems was low. According to Kyama et al., this result is possibly due to unique lifestyles (heightened risks for pelvic inflammatory disease, early pregnancies, and blocked Fallopian tubes) and the lack of proper medical facilities and education. Kyama et al. mentioned that endometriosis-related ascites and cervical endometriosis seemed more frequent in African American and African-Indigenous women. In a second study, Kyama et al. (2007) summarized the following issues that may have contributed to few diagnosed cases of endometriosis in the African-Indigenous community:

- lack of awareness about endometriosis as a health problem among treating physicians
- poor access to facilities that could perform laparoscopic procedures
- limited training in diagnosing and treating endometriosis
- lifestyle factors that possibly contribute to African-Indigenous women's protection against endometriosis

Shade et al. (2012) did a 10-year retrospective study to localize implantation sites for endometriosis to analyze patient charts. The findings showed that African American women seemed to have a higher proneness to uterine endometriotic implants. The study also articulated findings that reflected themes in previous studies regarding racial differences in endometriosis diagnosis and characteristics of endometriosis. Shade et al. proposed reasons for disparities as lifestyle, immunological factors, and other factors (i.e., differences in genetic variations, environmental and socioeconomic factors, or body mass index and nutrition). However, regardless of the motivation for racial disparities in African American women with endometriosis, Shade et al. asserted that the findings in their study warranted further research on this population.

Roomaney et al. (2020) analyzed the biopsychosocial predictors of depression symptoms in South African women with endometriosis. Roomaney et al. stated that elevated symptoms of depression have historically been associated with CPP and endometriosis. In keeping with this assertion, the study showed that 43.1% of the participants in their study reported escalated depressive symptoms, which also aligns with findings in older studies (see Chen et al., 2016; Lagana et al., 2017; Sepulcri & Amaral, 2009). Overall, the review also established a relationship between depression, anxiety, psychosocial stress, quality of life, and endometriosis among the participants. Specifically, Roomaney et al. found that 43.1% of the women had moderate to severe depression and expressed negative feelings about the medical profession, sexual relationships, and physical functioning, which were predictors of depression, physical functioning being the most significant predictor. Roomaney et al. asserted that studies had demonstrated the correlation between anxiety and depression, and pelvic pain. However, Roomaney et al. stated that no existing studies analyzed physical limitations as a predictor of depression in women with endometriosis. Therefore, this study was unique in identifying a subject that required more research in the study’s population. This study implied that medical practitioners must show empathy when treating women in this population and consider the factors contributing to their distress, mitigating the adverse impact to protect them from additional harm.

Endometriosis Symptom Management During COVID-19 Restrictions

The health care barriers associated with the COVID-19 pandemic undoubtedly imposed the burden of undue stress on individuals with chronic illnesses, such as endometriosis. Leonardi et al. (2020) discussed COVID-19 restrictions, possible anxieties, and increased stress associated with the virus exacerbating endometriosis symptoms; concerns about determining when urgent care is required; and self-management strategies as a supplement or substitute for medical treatment to address these issues.

Roomaney & Kagee (2016) compartmentalized strategies as problem-focused and emotion-focused because women with endometriosis typically used both emotion- and problem-based strategies to cope with their symptoms. Similarly, Leonardi et al. (2020) stated that women diagnosed with endometriosis who employed positive problem-centric coping strategies experienced and reported gains in lowering depression and stress levels. Leonardi et al. mentioned that the strategies reduced dysmenorrhea and CPP and stated that the central purpose of these strategies was to feel in control, minimizing concerns of pandemic-related health threats. Leonardi et al. listed endometriosis education, work and study management (including modifications during times of pain exacerbation with employers and school administrators), social activities, social support, sleep (proper sleep hygiene), physical exercise, yoga, pelvic exercise and physiotherapy, diet (anti-inflammatory, gluten-free, and low FODMAP diet consideration), heat (heat patches for 8 to 13 hours at a time), and cannabis (medicinal cannabis with legal access) as problem-focused strategies.

Regarding emotion-focused strategies, Leonardi et al. (2020) explained that emotion-focused strategies helped people with endometriosis to manage the negative psychological impact compounded by COVID-19-related worries. Emotion-focused strategies mentioned were practicing relaxation and mindfulness, engaging in Acceptance and Commitment Therapy (ACT), and adopting a positive attitude. This study briefly and thoroughly addressed endometriosis symptomatology and concerns that COVID-19 limitations might have compounded. It acknowledged that COVID-19 might have triggered negative feelings and caused barriers to traditional care modalities. It also proposed strategies that targeted physical and mental health needs that women with endometriosis might have faced before and during the pandemic.

Summary and Conclusion

This chapter of this qualitative study thoroughly reviewed literature related to the nature of endometriosis and how it impacts women’s lives and relationships, including during the pandemic. The literature review also includes limited research regarding how endometriosis has impacted Black women and the history of Black women and health care in the United States.

Just as researchers must carefully interpret transcripts; accurately identify key terms, phrases, and themes; and deploy strategies to achieve trustworthiness in research, medical providers must develop the ability to identify critical terms indicating pain and distress when communicating with their patients. Existing research findings supported the critical nature of health care providers understanding key terminology indicative of patients communicating their pain.

Bullo and Hearn (2021) conducted a qualitative study using semistructured interviews with 21 participants diagnosed with endometriosis aged 23 to 53 years. Like other studies, this study found that the women had endometriosis symptoms for an average of 11 years before receiving a formal diagnosis indicating a delayed diagnosis. Because endometriosis-related pain was challenging to describe, Bullo and Hearn aspired to understand how patients might have used metaphors in communicating their pain. The research resulted in the identification of seven conceptual metaphors used in 221 expressions articulated across the participants. Three themes related to the women's experiences were discovered: unimaginable pain, vulnerability and helplessness, and the motivation to hide and manage pain simultaneously. The seven key metaphors most used by the women (in order of most to least frequently used) included them describing pain as physical properties of elements, physical damage, the external animate agent causing physical damage, transformative force, external inanimate entity, sensory experience, and animate agent. Examples of the seven metaphors expressed by the women included feeling pressure, electric force, or tension; stabbing or twisting sensations; the feeling of being cut; feelings of being doomed or possessed; having sensations like metal wool is inside, machine-like; feeling like a loud car alarm is going off or nails moving against a chalkboard; and feeling nagging pain or like the womb is angry.

The clinical implications of this study included the significance of health care professionals understanding the critical nature that language plays in doctor-patient communication and medical settings. The study demonstrated that health care providers have to be sensitive to how endometriosis patients articulate their symptoms and feelings because it could prevent the minimization, dismissal, and misinterpretation of their pain (Bullo & Hearn, 2021). This study also highlighted that provider attentiveness could prevent other harmful actions and detrimental outcomes, such as delayed or inappropriate diagnosis and deferred treatment.

Understanding key themes in describing endometriosis pain can facilitate health care professionals' gaining a deeper understanding of their patients' experiences and needs. Doctors being equipped with medical education and including (as opposed to dismissing, excluding, and devaluing) women and their knowledge of their bodies is critical in endometriosis patients’ developing trust and confidence in the doctor’s competence. Taking this extra step could also result in the patients receiving the degree of care that they need (see Young et al., 2020). Moreover, providers must incorporate sensitivity related to Black women’s cultural and other experiences (i.e., the SBWS, intersectionality, and racial disparities in the U.S. health care system) that perpetuate harmful coping mechanisms and inadequate treatment.

Chapter 3: Research Method

In this qualitative study, I attempted to gain a deeper understanding of the perceived experiences of Black women living in the United States who have endometriosis-related symptoms, specifically regarding how coping with endometriosis during the COVID-19 pandemic may have impacted their level of mental health care. I sought to comprehend how Black women's perceived level of care may have differed during the COVID-19 pandemic (compared to before the pandemic) and how their perceptions may differ from others' perceptions. I sought to understand Black women's experiences with endometriosis symptoms during the COVID-19 pandemic, particularly how they viewed their level of medical and mental health care and how they managed their symptoms during this time. I sought to understand whether their perceived level of care differed during the COVID-19 pandemic compared to before.

Overall, I aspired to fill a gap in the literature on this topic. I hoped to enlighten mental health and medical providers regarding Black women's feelings regarding their health care experiences with endometriosis before and during the pandemic restrictions. To gather data for this study, I conducted individual semistructured interviews with eight Black women who live in the United States. This chapter addresses the research design and rationale, the researcher's role, the study's methodology, issues of trustworthiness, and a summary.

Research Design and Rationale

This section presents the research questions I strove to answer, the research design and rationale, and the design limitations. The research design and questions were appropriate for a qualitative study. This section demonstrates this alignment and addresses the rationale for selecting the research design to answer the qualitative research questions.

Research Questions

The research questions embodied what this study attempted to reveal, aligned with qualitative methodology, and influenced the type and breadth of knowledge produced for this study’s purpose, scope, and nature. The research questions that guided this study were as follows:

RQ1: What are the lived experiences of Black women with endometriosis during the COVID-19 pandemic?

RQ2: How do Black women manage their endometriosis-related symptoms during the COVID-19 pandemic?

RQ3: How do Black women perceive their mental health and medical care for endometriosis-related symptoms during the COVID-19 pandemic?

Research Design

I examined the perceived experiences of Black women with endometriosis regarding their level of care in the United States during the COVID-19 pandemic. Therefore, qualitative methodology was most suitable for this study’s topic. Qualitative methodology allows the researcher to understand how people construct their experiences (Merriam & Tisdell, 2016). Merriam and Tisdell stated that a basic qualitative design focuses on meaning and understanding and includes a purposeful sample. Merriam and Tisdell elaborated that qualitative studies include data collection through interviews, documents, and observations, and data analysis is inductive and comparative. Merriam and Tisdell also mentioned that findings in qualitative studies include detailed descriptions that are presented as themes. Alase (2017) stated that qualitative methodology facilitates the exploration and investigation of phenomena. Alase expressed that qualitative methodology allows researchers to engage their subjectiveness and relational skills in an investigatory research process.

Husserl (1931) originally conceptualized phenomenology as a qualitative approach to facilitate the comprehension of people's lived experiences and the meaning of those experiences within specific contexts (as cited in Alase, 2017). Alase (2017) explained that an IPA provides researchers the opportunity to comprehend an in-depth account of participants' lived experiences. Alase also stated that this design allows participants to provide a narrative to express their firsthand stories without distortions.

Rationale

A qualitative IPA research method was appropriate for the current study because I explored the underlying structure of a particular phenomenon: Black women's perceived experiences with health care while experiencing endometriosis symptomology during the COVID-19 pandemic. I opted to use IPA in a qualitative approach because it accommodated multiple participants who experienced the same phenomenon and motivated them to tell their stories without prosecutions or distortions. IPA also allowed me to interpret the meaning of those lived experiences. This method goes beyond the scope of being a general inductive approach because it generates richer and more in-depth data collection, descriptions, and analysis processes (Alase, 2017). An IPA allowed me to create a space in which participants could freely tell their stories while sharing how the phenomenon impacted their lives.

I conducted virtual semistructured interviews with eight participants to collect rich and detailed information. This technique enabled rich data collection from participants through one-on-one interviews using open-ended questions that generated considerable data for analysis. This qualitative approach provided Black women with the opportunity to share their lived experiences with having endometriosis, including how it impacted their mental health while having the disease during the COVID-19 pandemic.

Role of the Researcher

As a qualitative researcher for a phenomenological study, my responsibility was to investigate and interpret the participants' lived experiences and the impact of the phenomenon on their lives (Alase, 2017). My role was to think through every aspect of the study and attempt to foresee problems (Creswell, 2012). I had to pay attention to sensitive issues and how the personal nature of endometriosis might have emotionally impacted participants' ability or willingness to answer interview questions. As the researcher, I had to be mindful of this study's sensitive nature, be empathetic toward participants' feelings, and be respectful of their boundaries.

Wu and Wu (2011) mentioned that qualitative researchers must focus on analyzing the context of the phenomenon, explore the root cause, and feature the explanations of what occurred. Flick (2010) mentioned that qualitative researchers should understand the connection between the method and the issue at hand. As an IPA researcher, I optimized the opportunity to explore participants' lived experiences deeply and meaningfully without introducing distortions, reported accounts, or feelings of judgment (Alase, 2017). Moustakas (1994) stated that the role of the researcher is to remove biases, prejudgments, and preconceived notions about elements they are attempting to understand.

Methodology

For this study, I used an IPA to facilitate an understanding of Black women's lived experiences with having endometriosis symptomology during the COVID-19 pandemic and how it might have impacted their mental health. As a qualitative research methodology, the IPA enabled me to use interpersonal skills to do in-depth exploratory research and form a relationship with the participants (Alase, 2017). This advantage facilitated asking clarifying, probative, and follow-up questions throughout the process.

Moreover, Alase (2017) stated that an IPA was ideal for me as a novice researcher because it allowed me to obtain deeper exploratory information regarding the participants' lived experiences. An IPA is a traditional qualitative approach; it is used to explore how people interpret or make sense of their lived experiences (Smith et al., 2009, as cited in Alase, 2017). Therefore, it was the most appropriate methodology for the purpose of this study.

Participant Selection

The population I selected for this study was Black women living in the United States. The population included Black women between 18 and 40 years of age who had a medical diagnosis of endometriosis and experienced its symptomology requiring physical or psychological attention during the COVID-19 pandemic. I selected this age range because, according to a 10-year study of endometriosis in the Black African populations, endometriosis was typically discovered at the height of Black women’s reproductive period when they are in their 20s and 30s (Ajayi et al., 2016). In addition, Ajayi et al. stated that women between 40 and 50 years of age are the most infrequent among Black women to be diagnosed with endometriosis.

Race, gender, age, and citizenship were the only demographic factors considered when selecting participants with endometriosis for this study. The participants had to identify as Black women between 18 and 40 years of age who were legal U.S. citizens and diagnosed with endometriosis. Moreover, the participants had to have experienced endometriosis symptoms during the COVID-19 pandemic. Religion, birthplace, and other demographic factors were not considered for this study and may have served as limitations to the findings and considerations for future studies.

Sampling Criteria and Strategy

I recruited participants by using my judgment regarding the criteria and employing nonrandom purposeful and snowball sampling. I used these strategies to develop a participant pool because I had to collect the data aligned with the research questions, methodology, and theoretical foundation. Because this was a qualitative study, I had to select participants who met the criteria and could provide the rich and in-depth data required for an IPA study.

Alase (2017) stated that a phenomenological study should include two to 25 participants representing the existing homogeneity in the participant pool. Alase explained that an IPA study should be conducted using unstructured or semistructured interviews but should not include fewer than two participants. In addition to using a small participant pool, Alase stated that IPA researchers should focus on participant homogeneity to gain more traction with understanding the participants’ overall perceptions of their lived experiences. Alase also emphasized that the homogeneity and small size of the participant pool allow IPA studies to be detailed and robust in the analytical process.

Based on this recommendation, I recruited 12 participants who met the selection criteria. However, only 8 participants were included in the study. I recruited participants through online advertisements and focused on Black women with endometriosis to sign up as participants. I posted the advertisement on Facebook and Instagram pages for groups of Black women with endometriosis. After gathering information for the respondents to the advertisements, I had initial phone conversations with the respondents to confirm that they met the criteria and were willing to participate. After selecting 12 appropriate candidates for the study, I distributed a demographic questionnaire to collect the participants’ demographic data. After collecting the demographic data from the potential participants, I communicated with the participants who fit the selection criteria for the study and scheduled interview dates and times. I audio-recorded the interviews for 12 participants; however, only eight recorded interviews qualified for the study. One participant admitted that she worked in the United States but was a legal resident of Canada. Another participant stated that she had not been officially diagnosed with endometriosis but had received an informal diagnosis. The other two participants were excluded because they did not have endometriosis symptoms during the COVID-19 pandemic. These two participants had endometriosis symptomology earlier in life, so I excluded their interviews. For the four candidates who did not qualify, I ended the recording and thanked them for their consideration. Then I transcribed, organized, explored, and coded the data I collected from the eight qualified participants by arranging frequently mentioned words, terms, and concepts into themes and subthemes.

Instrumentation

I used two instruments for this study: a demographic questionnaire and a semistructured interview protocol. I used the demographic questionnaire to identify the participants’ gender, age, race, and citizenship. I administered the semistructured interviews using a virtual interviewing technique via Zoom business technology to collect data that aligned with the research questions. I asked questions to assess whether the participants had CPP or other endometriosis symptoms that required them to seek medical or psychological care during the COVID-19 pandemic and how they perceived their level of care. I posed questions that elicited detailed responses regarding endometriosis symptomology (including the duration, onset, severity, and diagnosis) and revealed how the participants perceived living with endometriosis during the pandemic. I also probed to discover how having endometriosis symptoms during the COVID-19 pandemic might have impacted the participants’ mental health and how they experienced receiving medical and mental health care during pandemic restrictions.

Recruitment, Participation, and Data Collection Procedures

I recruited Black women who lived in the United States, its territories, or the federal district of Washington D.C. who were diagnosed with endometriosis and were between 18 and 40 years old. The recruited participants had experienced endometriosis symptoms during the COVID-19 pandemic. I recruited eight qualified participants by advertising the details of the study on the social media platforms Facebook and Instagram. I targeted sites on social media applications that were designed to support Black women who have endometriosis. In the advertisement, I attracted recruits by describing the study's purpose and emphasizing the study's possible benefits. The advertisement also included the dates for the study and interview duration, which was between 60 and 90 minutes and was typical of an IPA study (Alase, 2017). I aligned my recruitment actions with the American Psychological Association (APA, 2012) ethics code for research and publication and obtain informed consent by using an informed consent form. I explained to the participants the purpose of the research, the estimated duration of the interview, procedures for the study, their right to decline or withdraw from the study, the study's benefits and limitations (including confidentiality), and incentives for participating (APA, 2012). When inviting participants to the interview, I sent out individual interviews to each participant. As Alase suggested, as a researcher who is ethically obligated to protect human subjects' rights, privacy, and dignity, I protected the participants from harm to the greatest extent possible. To compensate the participants for their time, I gave them each a $25 gift card.

Data Analysis

Because this study involved qualitative research that included rich data, I used Zoom business technology to automatically transcribe the audio-recorded interviews. I copied the transcribed interviews onto blank Word documents and edited them for accuracy. I saved the original transcriptions for future reference. Next, I read and analyzed the interview transcriptions to understand how each participant felt and perceived their experiences.

Alase (2017) suggested that reading through the interview responses to identify common themes (searching for keywords) narrows down the content of the transcripts. Therefore, I read through the transcripts several times to identify standard codes, searching for key phrases or words that might have been repeated in participants' stories. Then, I recorded identified themes among the codes and key phrases. I imported the data into NVivo qualitative data analysis software by QRS International, which is designed to organize, analyze, and discover themes in data from interviews, such as the semistructured interviews I used for this study. The NVivo software facilitated a thematic analysis by identifying themes that aligned with the research questions presented in this study. As Creswell (2013) suggested, I also recorded my experiences related to Black women having endometriosis during COVID-19 to increase my awareness of my biases and prevent including my subjective experiences in the phenomenon. As Creswell recommended, I developed a list of significant and impactful statements from the participants to use as a foundation for understanding the phenomenon. After coding, identifying, and categorizing themes for the study, I safeguarded the data and information for future reference and the protection of participant confidentiality.

Issues of Trustworthiness

Korstjens and Moser (2018) expressed that credibility, dependability, transferability, and confirmability are all quality criteria for trustworthiness in traditional qualitative research methodologies. Trustworthiness refers to whether the study's findings can be trusted. Korstjens and Moser elaborated that reflexivity is critical to ensuring the quality and transparency of qualitative research.

Mason (2002) insisted that trustworthiness includes data production and analysis that is appropriate for the research questions and includes research that is thorough, honest, and accurate in data representation. I was mindful that trustworthy research should be free of biases to the highest degree possible.

The IPA researcher has two roles: the empathetic observer recording the participants' perspectives and the explorer of the participants' experiences, which includes the researcher's perspective (Rodham et al., 2015). Rodham et al. stated that the researcher's obligation in terms of trustworthiness is to have the capacity to work alongside the participants and objectively interpret what they are reporting. Moreover, superior qualitative research should also be sensitive to context, demonstrate rigor and dedication, be transparent and coherent, and be relevant and impactful (see Rodham et al., 2005; Rolfe, 2006). This section explored the critical concepts of trustworthiness for this study and their significance regarding its legitimacy.

Credibility

Credibility refers to the confidence in the internal validity of research findings and how well they adequately interpret and represent the participants' reported views (Korstjens & Moser, 2018). Korstjens and Moser stated that credibility concerns truth value and includes four strategies: prolonged engagement, persistent observation, triangulation, and member check. I used triangulation and member check techniques to achieve credibility in this study.

Korstjens and Moser (2018) explained that triangulation is a strategy used to strengthen qualitative research that can be achieved through methodological, data, and investigator triangulation. I used methodological triangulation for this study by gathering data through recorded interviews, field notes, and journaling. I practiced data triangulation by gathering data at various times of the day. Lastly, I relied upon my chair and dissertation committee to perform a secondary investigation of my coding analysis, data interpretations, and decisions to achieve investigator triangulation.

Member check encompasses researchers vetting their data, analysis, interpretations, and findings through the participants from which the data originated (Korstjens & Moser, 2018). Member check fortifies researchers' data and findings and enables credibility by gaining consensus from reporters through their cognitive lenses. I used the member check technique by sharing transcripts and critical statements and identified key terms and themes with the participants for their perusal and feedback. This strategy allowed me to identify any misinterpreted data and correct it.

Transferability

Transferability refers to the extent to which qualitative research findings can be transferred to other settings or contexts with other participants (Korstjens & Moser, 2018). I used thick description as a strategy to achieve transferability in this study. Korstjens and Moser explained that a thick description strategy includes describing the experiences and behaviors within specific contexts to make the experiences and behaviors more meaningful to the observer. This study gathered rich, descriptive data about women with endometriosis and considered cultural and contextual components because the participants were Black women living in the United States who experienced endometriosis symptomology during COVID-19. This study also examined the underpinnings of how Black women may have experienced this phenomenon differently within the prescribed contexts. Because variation is a critical component of transferability, I gathered detailed data through in-depth interviews with Black women of varying ages, religious or spiritual beliefs, and socioeconomic statuses living in various parts of the United States.

Dependability

Dependability refers to the consistency and stability of the study’s findings over time (Korstjens & Moser, 2018). Korstjens and Moser stated that this aspect of trustworthiness can be achieved by triangulation and audit trail strategies. Korstjens and Moser also explained that an audit trail involves transparently disclosing the research steps employed from the beginning of the study to the development and reporting of the research findings and maintaining records of the research path throughout the study. To achieve dependability in this study, I kept a journal of my research journey and steps from the beginning to completion, including data collection, organization, categorization, and notes for future reference and replication. I also used the code-recode technique and asked a peer to critique my research process.

Confirmability

Confirmability is the degree to which other researchers can confirm the study’s findings derived from the research data (Korstjens & Moser, 2018). Korstjens and Moser explained that, like dependability, confirmability can be attained by establishing an audit trail. I achieved confirmability by maintaining records of my research process throughout the entire duration of the study.

Reflexivity

Reflexivity refers to the researcher examining and reflecting on their own implicit and explicit biases, assumptions, values, and preconceived notions and how they might impact data and information interpretation and decision making throughout the study (Korstjens & Moser, 2018). I used a journal to annotate any observed biases or preconceptions that could have adversely impacted my objectivity and the credibility of other aspects of the study’s trustworthiness.

Ethical Procedures

I initially consulted the Walden University Institutional Review Board (IRB) to follow APA ethical procedures for research and publication. The IRB approved my study methodology, the participant population, the procedures and tools for recruiting, interview instruments, cooperation agreements, and consent forms (IRB approval #07-15-22-0730544). Once I attained approval from the IRB to conduct a study with the elected population using the procedures, forms, and instruments that I had developed, I proceeded with recruiting participants for the study.

To practice ethical procedures, I ensured that my informed consent form emphasized the benefits of the study and the voluntary nature of participation and the right to withdraw at any time. Per ethical guidelines, informed consent included the purpose of the study, the duration of the study, and the procedures throughout the process. The form also included the limits of confidentiality, participation incentives, and details regarding compensation for time. I also addressed the sensitive nature of the research topic and foreseeable factors that might have caused discomfort during the interviews. The informed consent also elicited participants' agreement to be audio-recorded during the interviews.

Regarding safeguarding, I kept all raw data on a protected flash drive and ensured that my laptop was password protected and secured in the safe in my office when not in use. All relevant information, including raw data and transcripts, journals, recordings, forms, and other research documents, was maintained and stored in a locked safe when not used for research purposes. I will retain the data for seven years, after which I will destroy the documents.

Summary

I used a qualitative (IPA) approach to discover an in-depth understanding of Black women's perceptions of their mental health and care level while having endometriosis symptoms during COVID-19. I used a semistructured interview to record and analyze self-reported answers to this study's three qualitative research questions that address a gap in existing literature regarding Black women and their experiences with having endometriosis in the United States during the COVID-19 pandemic. This research process included conducting confidential and private interviews with willing participants, recording and documenting transcripts, coding information, and identifying themes to present the study’s outcome as they aligned with the research questions. I recruited participants through non-random purposeful sampling and snowball sampling. The participants I recruited were Black women, who are United States residents between 18 and 40 years old, experiencing endometriosis symptomology during COVID-19.

Regarding the study’s trustworthiness, I achieved credibility through triangulation and member checking, including data gathering at contrasting times and reliance upon a secondary investigation of my coding and data analysis and fact-checking with participants, respectively. I achieved transferability by using thick description and variation in the participant pool. To acquire dependability, I strove for stability and consistency by maintaining a journal chronicling the steps of my research from the start through completion. Also, I used a code-recode technique to achieve dependability. Confirmability was attained through an audit trail, while reflexivity occurred through journaling observed biases and preconceived ideas.

This chapter also includes ways that I, as the researcher, employed ethical procedures throughout the research process. I obtained the IRB’s approval for my research rationale, including the methodology, participant population, interviewing techniques and tools, consent forms, and other documents. Following the APA ethical guidelines, I also had clients sign consent forms acknowledging the sensitive nature of the research, emphasizing the study’s benefits, and assuring participants of privacy and confidentiality. I also compensated participants for the time that they dedicated to the interviews. Lastly, I safeguarded all relevant research material per APA ethical guidelines and will destroy all documents in seven years.

Chapter 4: Results

This qualitative phenomenological study was designed to explore and gain a more profound understanding of the mental health of Black women with endometriosis-related symptoms during the COVID-19 pandemic and how having this symptomology during the pandemic might have affected these women and their lives. In this chapter, I provide an analysis of the findings resulting from eight semistructured interviews conducted virtually via Zoom business technology. I asked 23 open-ended questions in the virtual interviews to collect rich data. I asked questions regarding when participants were diagnosed with endometriosis, when the symptomology occurred, the nature of the symptoms, their perceived level of care before and during the COVID-19 pandemic, the most challenging thing about having endometriosis, and experiences with the SBWS. I conducted the interviews, which lasted up to 70 minutes, using open-ended questions to allow more flexibility and richness in participant responses. The research questions that guided the study were as follows:

RQ1: What are the lived experiences of Black women with endometriosis during the COVID-19 pandemic?

RQ2: How do Black women manage their endometriosis-related symptoms during the COVID-19 pandemic?

RQ3: How do Black women perceive their mental health and medical care for endometriosis-related symptoms during the COVID-19 pandemic?

This chapter presents the analytical findings of the interview data and encapsulates relevant themes that surfaced from the analysis. This chapter also includes the research setting, participant demographics, data collection and thematic analysis processes, evidence of trustworthiness, results, and a summary.

Research Setting

Participants were interviewed from August 5, 2022, through August 26, 2022. To recruit participants, I advertised the flyer on multiple pages for endometriosis support groups on Instagram and Facebook. I messaged administrative contacts for multiple endometriosis groups, thanking them for their time and consideration, acknowledging their work in supporting their members with challenges related to endometriosis, and attaching the flyer to the personalized messages. After gaining access to the group pages, I advertised the flyer to recruit participants. I also promoted the study on social media to reach individuals who had endometriosis or had friends or family members who had endometriosis during COVID-19 but might not be a part of the support group. Once I vetted the qualifications for the women who expressed interest in participating and determined their eligibility, I obtained their electronic consent. Then I scheduled them for one-on-one semistructured interviews via Zoom.

I opted to conduct interviews virtually for participant convenience and safety, given the nature of endometriosis and the graveness of the COVID-19 pandemic and its potentially harmful impact on humans, particularly those in the African American community, and especially Black women. Black Americans have contracted COVID-19 at higher rates than other races and are more likely to experience complications or death (Walton et al., 2021). Walton et al. also expressed that Black women are more likely to die after contracting COVID-19 due to lack of access to affordable health care.

Moreover, Walton et al. expressed that Black women bear a financial and mental burden directly correlated with the COVID-19 pandemic and systemic racism that overlaps with other oppressive systems. Therefore, I decided to conduct virtual interviews with the research participants.

I conducted the virtual interviews in a private and secure location in my home office. I live alone, so no one else was in my home. The interviews were audio-recorded and transcribed using Zoom business technology. I also observed the participants' facial expressions, reactions, emotional responses, and other nonverbal cues. Seven participants agreed to have the video on during the interviews, and one participant chose not to have the video on during the interview. All interview meetings transpired smoothly without interruptions, and none of the participants appeared emotionally distressed during the interviewing process.

Demographics

The participant pool was limited to Black women from 18 to 40 years old who were residents of the United States and had been formally diagnosed with endometriosis. The participants ranged from age 18 to 37, and they resided in multiple locations in the United States including South Carolina, Indiana, Nebraska, Texas, Missouri, and Maryland. The participants' educational levels ranged from high school graduate to advanced degree. Only one participant was married, and six were single. Another participant had been in a partnership for 6 years. The eight participants were recruited using purposeful and snowball sampling, which enabled the selection of a diverse and qualified participant pool. The recruitment flyer contained relevant information about the study for the participants' consideration. Table 1 contains participant demographics including age, ethnicity, gender, marital status, employment status, location, and education level. Participants were identified using pseudonyms to protect their privacy and maintain confidentiality. All selected participants self-reported being formally diagnosed with endometriosis by a health care provider.

Table 1

Participant Demographic Information

Participant - assigned pseudonym	Age	Ethnicity	Gender at birth	Marital status	Employment status	Location	Education level
PRT1	33	Black or African American	Female	Single	Part-time	Indiana	High school graduate
PRT2	18	Black or African American	Female	Single	Part-time	Nebraska	Some college
PRT3	26	Black or African American	Female	Single	Full-time	Texas	Vocational/ trade/tech
PRT4	32	Black or African American	Female	Single	Full-time	Texas	Bachelor's degree
PRT5	32	Black or African American	Female	Single	Full-time	South Carolina	Advanced degree
PRT6	27	Black or African American	Female	Single	Part-time	Texas	Advanced degree
PRT7	37	Black or African American	Female	Married	Full-time	Missouri	Bachelor's degree
PRT8	26	Black or African American	Female	Single	Part-time	Maryland	Some college

Data Collection

Data collected for this study included information gathered from eight virtual semistructured interviews. The participant sample was eight women between 18 and 40 years old who identified as Black or African American and were diagnosed with endometriosis requiring care during the COVID-19 pandemic. My original plan was to include 12 participants. However, of the 12 participants I interviewed, only eight qualified. An IPA study should consist of two to 25 participants representing homogeneity in the participant pool (Alase, 2017). Alase noted that an IPA study should include unstructured or semistructured interviews and cautioned that it should include at least two participants. The eight participants selected for my phenomenological study met this professional recommendation.

The virtual interviews lasted between 35 and 70 minutes and were held at various times of the day between 10:30 a.m. and 7:00 p.m. Eastern/Standard Time. The interviews were audio-recorded, transcribed automatically, and saved using Zoom business technology. During the interview, I asked the participants 23 questions (see Appendix B) including clarifying questions to gain a clearer understanding of participant responses. During the interviews, I paid close attention to participants' emotional states and displayed behaviors indicating that I was paying attention closely to what they were stating, often repeating statements for accurate comprehension. I also provided clarification of the questions for participants when requested. After each interview concluded, I asked each participant if there was anything they would like to add regarding their experiences with endometriosis during the COVID-19 pandemic that we might have missed during the interview; most interviewees had no additional information to add. Several interviewees provided additional information related to questions asked earlier during the interview. Before disconnecting the Zoom meeting, I thanked the participants for their time and assured them they would receive their gift cards immediately after the session concluded. I also informed them that I would provide them with a clean version of the transcriptions within 1 week after the interview.

After each meeting, I removed the time stamps from the transcriptions and listened to the audio recording to edit the content for accuracy. There were many discrepancies between the recording and the transcript that had to be edited, so I edited the transcripts immediately after each meeting concluded while the interview was fresh in my memory. I provided all participants with clean, edited copies and asked that they inform me of any issues, questions, or concerns that they had about the transcript. Most participants thanked me, and none of them expressed any concerns regarding the transcripts. Next, I used NVivo software to examine the data and organize it into categories for detailed thematic analysis.

Data Analysis

The data analysis phase included the organization of documents for reviewing and the use of NVivo software for data analysis resulting in codes and subsequent categories and themes. First, I read and reread transcripts and repeatedly listened to audio recordings. Then, I manually performed open coding, read informant responses, and arranged similar themes into broad thematic categories by color coding the themes (see Williams & Moser, 2019). Then, I watched numerous NVivo software tutorials to gain a better perspective of the diverse types of coding that can be done using the software. Next, I secured an NVivo subscription and entered the transcripts, codes, and subcodes into NVivo. I then identified participant phrases aligned with themes and appropriately coded them. I took notes for any additional themes that may have emerged. For example, while reading transcription entries related to an identified category (health care), I recognized another emerging theme regarding insurance and treatment affordability. I also acknowledged another theme after the fact related to research and resources. I was interested in knowing what words were most frequently used throughout the interviews, so I organized all of the participant interviews by question and participant pseudonym into a single Word document and uploaded it into NVivo. Then, I performed a word frequency query to obtain visuals of the frequency of words included in the transcripts, grouping stemmed words and extracting small words (e.g., “like” or “liked”). I also considered the word tree when coding data. I removed the word “like” and its variations because it was the most represented word in the transcript and overshadowed more powerful words in the Word cloud image. The top 10 most used words were: “knows,” “just,” “think,” “feel,” “really,” “pains,” “yeah,” “lot,” “things,” and “kinds.” Most impactful was discovering that the word “pain” was used over 160 times in the transcripts, and the word “endometriosis” was used 269 times. Figure 1 represents the Word Cloud that resulted from the query in NVivo.

Figure 1

NVivo Word Query Word Cloud Representation

Evidence of Trustworthiness

Trustworthiness refers to the degree to which a study’s findings can be trusted, including the quality criteria of credibility, dependability, transferability, and confirmability (Korstjens & Moser, 2018). Korstjens and Moser stated that reflexivity is critical to developing a quality, transparent qualitative study. Rodham et al. (2015) discussed that researchers explain how they conducted IPA research. Rodham et al. stated that researchers need to express how their analytical process is trustworthy. Rodham et al. recommended that researchers listen to the audio recordings when attempting to analyze data to prevent them from projecting their interpretive biases onto the data. Rodham et al. also suggested that audio recordings should be maintained in case secondary analysis is needed. An essential process in establishing trustworthiness is listening and relistening to the audio recordings, which I did throughout the analytical process for the current study. I also noted my biases before conducting interviews and analyzing the data and was consciously aware of my biases throughout the research process. The critical elements that addressed trustworthiness in this study included credibility, transferability, dependability, confirmability, and reflexivity.

Credibility

I used triangulation and member checking to establish the internal validity of the research findings for credibility, which refers to research findings and how adequately they represent and interpret participants’ reported narratives (Korstjens & Moser, 2018). Throughout the data gathering, coding analysis, data interpretation, and decision making processes, I exercised due diligence in capturing and interpreting participant reporting. I carefully recorded the interviews using an audio recorder on my smartphone and Zoom business technology. I also audio recorded the interviews and had them automatically transcribed using Zoom.

Throughout the interview process, I recorded notes and gathered data at various times of the day. I listened to the audio recordings at least three times each, reviewed and rereviewed transcriptions, and edited them for accuracy. I then sent copies of the transcripts to the participants for their review and confirmation. All of them agreed with the transcription contents, and none of them requested corrections. Lastly, I relied on my dissertation chair and committee to do a secondary review of my analytical process, interpretation, and decision making.

Transferability

Transferability refers to the degree to which qualitative research findings can be transferred to other contexts or settings (Korstjens & Moser, 2018). I used thick description throughout the interview and interpretation processes. I collected rich and descriptive data from the participants and carefully considered the contextual and cultural components of their experiences. I gathered detailed data through in-depth interviews with Black women participants of various ages, socioeconomic and educational levels, and marital statuses. As a result, I ensured to document participant statements within their proper contexts, capturing the participants’ perceptions and sentiments throughout this study. For greater transparency, I used direct quotes based on transcripts approved by the participants to avoid data misinterpretation, capture the true essence of perceptions, and document participant experiences as accurately as possible.

Dependability

Dependability refers to the stability and consistency of a study’s findings over time (Korstjens & Moser, 2018). Triangulation was used to establish dependability. Also, I used an audit trail strategy to document the research steps of the study from the beginning to the end, in which I annotated the research path used throughout the study.

Confirmability

Confirmability is the point at which researchers can confirm research findings based on the data (Korstjens & Moser, 2018). Korstjens and Moser stated that confirmability is like dependability in that an audit trail can be used to establish it. Therefore, I used an audit trail and records maintenance plan during the entire study, taking notes and referring to the transcripts throughout the analytical and writing process.

Reflexivity

Reflexivity is the degree to which the researcher examines and reflects upon their assumptions, implicit and explicit biases, prejudgments, and values and how they might affect the researcher’s data interpretation and decision making (Korstjens & Moser, 2018). I used journaling to annotate any observed biases or judgements that could have impeded my impartiality and credibility, adversely impacting the study’s trustworthiness.

Results

This section of this chapter focuses on the results of the data analysis process and the categories and themes that surfaced after the coding process completion. Coding is ideal for qualitative research and includes processes for data collection, assembly and organization, categorization, and thematic sorting to construct meaningful interpretive analysis (Williams & Moser, 2019). Therefore, I used NVivo technology to code and identify themes in the transcripts and then categorized the themes, accordingly, as described above.

Altogether I developed roughly 80 codes which I was able to condense into four main themes and 14 related subthemes as follows:

- health (physical health, mental health, symptom management, delayed diagnosis, perceived level of care pre-COVID-19, and perceived level of care during the COVID-19 pandemic)
- life with endometriosis (the nature of endometriosis, the impact of endometriosis on their lives, and support system)
- the U.S. health care system (insurance coverage, resources and research, and overall quality of provider care)
- the nature of being a Black woman in the United States (the SBWS and the intersectional nature of being a Black woman in health care and other settings)

The themes aligned with and addressed the three research questions in this study as follows:

RQ1: What are the lived experiences of Black women with endometriosis during the COVID-19 pandemic?

RQ2: How do Black women manage their endometriosis-related symptoms during the COVID-19 pandemic?

RQ3: How do Black women perceive their mental health and medical care for endometriosis-related symptoms during the COVID-19 pandemic?

Table 2 breaks out the structure of the categories and themes that emerged from the data analysis. Table 3 through table 6 break out the frequency of participant endorsement of the themes and subthemes in the interview data, broken out by theme, subtheme, and participant.

Table 2

Identified Themes and Subthemes

Theme	Subtheme
Health	Physical health
	Mental health
	Symptom management
	Delayed diagnosis
	Perceived level of care (before the COVID-19 pandemic)
	Perceived level of care (during the COVID-19 pandemic)
Life with endometriosis	Nature of endometriosis
	Impact of endometriosis on their lives
	Support system
U.S. health care system	Insurance coverage
	Resources and research
	Overall quality of provider care
Nature of being a Black woman in the United States	SBWS
	Intersectional nature of being a Black woman in health care and other settings

Table 3

Frequency of Theme 1 (Health) Subthemes

Participant ID	Physical health (subtheme)	Mental health (subtheme)	Symptom management (subtheme)	Delayed diagnosis (subtheme)	Perceived level of care (before the COVID-19 pandemic) (subtheme)	Perceived level of care (during the COVID-19 pandemic) (subtheme)	Total
PRT1	1	1	1	1	1	1	6
PRT2	1	1	1	0	1	1	5
PRT3	1	1	1	0	1	1	5
PRT4	1	1	1	1	1	1	6
PRT5	1	1	1	1	1	1	6
PRT6	1	1	1	1	1	1	6
PRT7	1	0	1	1	1	1	5
PRT8	1	1	1	1	1	1	6
Total	8	7	8	6	8	8	45

Table 4

Frequency of Theme 2 (Life With Endometriosis) Subthemes

Participant ID	Nature of endometriosis (subtheme)	Impact of endometriosis on their lives (subtheme)	Support system (subtheme)	Total
PRT1	1	1	1	3
PRT2	1	1	1	3
PRT3	1	1	1	3
PRT4	1	1	1	3
PRT5	1	1	1	3
PRT6	1	1	1	3
PRT7	1	1	0	2
PRT8	1	1	1	3
Total	8	8	7	23

Table 5

Frequency of Theme 3 (U.S. Health Care System) Subthemes

Participant ID	Insurance coverage (subtheme)	Resources and research (subtheme)	Overall quality of provider care (subtheme)	Total
PRT1	1	0	1	2
PRT2	0	1	1	2
PRT3	1	0	1	2
PRT4	0	1	1	3
PRT5	1	0	1	1
PRT6	1	0	1	2
PRT7	0	0	1	1
PRT8	0	1	1	3
Total	4	3	8	16

Table 6

Frequency of Theme 4 (Nature of Being a Black Woman in the United States) Subthemes

Participant ID	SBWS (subtheme)	Intersectional nature of being a Black woman in health care and other settings (subtheme)	Total
PRT1	1	1	2
PRT2	1	1	2
PRT3	1	1	2
PRT4	1	1	2
PRT5	1	1	2
PRT6	1	1	2
PRT7	1	0	1
PRT8	1	1	2
Total	8	7	15

Themes

This section reviews the various themes that resulted from the analysis by theme, providing in-depth discussions about the categories based on first-hand accounts articulated by the research participants. The section will cover 14 categories organized into four themes (as illustrated in Table 2 above) and will also discuss areas where categories and themes have overlapped. The main themes addressed below that emerged from this body of research include health, life with endometriosis, the U.S. health care system, and the nature of being a Black woman in the United States. Table 1 contains the participants' assigned pseudonyms that are used in this section to introduce participants' narratives.

Health Factors

The main topic that surfaced throughout the interviews was the women's health, including their physical and mental challenges related to their symptomology before and during the COVID-19 pandemic. Participants discussed how they managed their symptoms when facing the COVID-19 pandemic restrictions. Also, seven women expressed that they had a delay in their diagnosis, which impacted their health and overall quality of life. Notably, one participant was 18 years old and was diagnosed with endometriosis shortly after her symptoms began. The categories discussed below include physical health, mental health, symptom management, delayed diagnosis, and the perceived level of care (before and during the COVID-19 pandemic).

Physical Health

All eight participants responded to questions related to their physical endometriosis symptoms. All but one of the participants, PRT1, talked about how painful endometriosis was, frequently referring to it as chronic or excruciating. PRT1 reported that she was diagnosed with silent endometriosis and had no pain. However, she discussed having physical symptoms – heavy and irregular periods and fertility challenges.

The word "pain" was mentioned over 160 times throughout the interviews and was the most referenced physical symptom. Other significant symptoms included clotting and heavy bleeding, mood swings, ovarian cysts, dyspareunia, irregular periods, dysmenorrhea, chronic back pain, mental distress, nausea, vomiting, sweats, passing out, dizziness, miscarriages, inflammation, hormonal fluctuations, fatigue, diarrhea, brain fog or memory loss, migraines, and bloating. Several of the women expressed that they had multimorbidity. For instance, one participant indicated that she had thoracic endometriosis, diabetes, and heart trouble; this participant was hospitalized for contracting COVID-19.

The most cited physical symptoms were chronic pain and dysmenorrhea, heavy clotting, mood swings, infertility issues, ovarian cysts, dyspareunia, mental anguish, and irregular periods. Participants described their physical pain by stating that it felt like a “brand-new” pain each day, requiring them to take excessive pain medication. Three participants mentioned that they took two to four times the recommended daily dose. Two participants stated that they were ingesting up to 14 pain pills daily; they acknowledged that the dosage was more than the prescribed one. They described the pain as persistent, debilitating, occurring much longer than their menstrual cycles. They also provided detailed accounts of how they would have to stay home because of the bleeding and the pain. Participants described the pain, heavy bleeding, and other symptoms similarly in the accounts included in this section.

PRT1 discussed how heavy her period was at times. She explained, “Oh, other than painful, I’ve just really pretty much been dealing with it.” She stated, “Sometimes I bleed so heavy I can’t even leave the house. I have to wear two pads and, within an hour, they're completely soaked. Like it keeps me busy. I don't know how else to put it. It's embarrassing."

PRT2 shared, "I've had really irregular periods, a lot of pain, a lot of chronic back pain. When I get sick, I have lots of diarrhea, lots of bloating, lots of nausea. I go to the bathroom all the time." PRT2 also commented on her experience with having complications related to COVID-19 contraction, comorbidity, and endometriosis as follows:

> I know I ended up having to be hospitalized because of all the conditions I have, and I didn't lose my smell or my taste. I just had really bad body aches. I couldn't move, I couldn't keep any foods or fluids down. It was kind of bad, and then on top of that, with me having heart problems and asthma, the doctors think that I have thoracic endometriosis, which is in the lungs.

PRT3 described her pain by stating, "Really not just regular like cramping but like I don't know how to explain it. Like excruciating type of cramping." She elaborated, "And then, of course, there's the mood swings and then, like the sweats, and nausea, vomiting, the passing out at times because of the pain, like multiple hospitals and stuff like that."

PRT4 stated, "But, yeah, for me, the mood swings and the pain." She mentioned that pain, blood clotting, and mood swings were the main symptoms and described her pain as "too much" despite her being active in sports in her youth. She told her experience with bleeding and pain as follows: "I feel like the heavy bleeding, and so, the pain and I mean like the chronic pain," PRT5 recounted her experience with endometriosis pain and other symptoms. She offered the following narrative:

> So, I have experienced, of course, I feel like the heavy bleeding, so, the pain and I mean like the chronic pain. So, yes, I normally experienced a lot of it in my back. So, my lower back definitely kills me. So, around my, I guess like my ovaries. Of course, further down, like, lower abdomen area. Like, I'm literally like hunched over. Like some days, I feel like that is the only way to get some relief. But even, what's it called (participant was thinking of what to call a heating pad)? A heating pad sometimes will literally do the trick between the front and the back. I try to figure out how I can make this work.

PRT6 stated, "I've experienced the really heavy cycles, the really, really bad cramps. I don't know if this is because of the cramps, but the feeling like I'm going to pass out. I get very lightheaded on my cycle." She also explained that she "never used tampons because they were painful." She stated, "Just thinking about the pain and how heavy my cycle is, and how heavy it was, and then developing a cyst was really scary." PRT6 also commented on her experience with having comorbidity and endometriosis as follows:

> And then in 2020, when COVID hit, I was having the worst time at my internship, the worst experience. It was my last two semesters. We went online to see clients, [and] clients are dropping out because they don't like online. I don't know if I'm going to graduate on time. Everything just fell apart. Everything fell apart. I was

> having these horrible migraines. So, on top of the endometriosis and being in pain from cramps, I was also having these horrible, horrible migraines.

PRT7 concisely described her symptoms. She stated, “I would say, heavy, heavy, heavy periods and irregular periods.”

PRT8 focused on her physical and mental anguish when describing her symptoms. She shared her symptoms as follows: “Pain. Chronic pain, fatigue, memory loss, I suppose, or memory fog. And probably like struggles with like anxiety and depression, which is more like the mental health side of things. Yeah, just mostly chronic pain and inflammation, really.”

Mental Health

All eight participants responded to questions related to their mental health related to endometriosis symptoms. Of eight participants, all but one of them (PRT7) expressed that they had experienced mental distress related to their symptomology. PRT7 did not go into detail about her mental health. She indicated that although she did not have any pain, she had concerns related to infertility that endometriosis had caused and wondered if she and her husband will ever be able to have children. Four of eight participants indicated they were diagnosed with anxiety and depression, and two stated that they were diagnosed with only depression. Of the two participants who said they have depression, one mentioned that she has anxiety but had not been formally diagnosed. Notably, two participants who reported having a mental illness were unsure if their anxiety or depression were related to their endometriosis pain. However, they discussed how the endometriosis symptoms influenced their mental health symptoms and that they sometimes co-occurred. However, several participants were unaware of the relationship between endometriosis, chronic pain, anxiety, and depression.

Moreover, half of the participants mentioned mood swings and hormonal fluctuations or imbalances when discussing mental health. Also, the participants attributed their mental illnesses to a host of issues, including wanting to be in control, pain, heavy bleeding, little to no support, a lack of people understanding their experiences, miscarriages or fear of future miscarriages, fear of their daughters having endometriosis, and infertility.

PRT1 described her mental anguish within the context of family planning. She stated, “Yeah, I have depression and high anxiety and stuff like that. Pretty much like I said earlier, the whole having a family aspect, it kind of does get me down sometimes. I get depressed.”

PRT2 stated, “I do suffer with depression and anxiety really bad.” She explained,

> I think, with everything going on, it’s caused me a lot of stress. You know, I’ve kind of had to learn how to deal with it. But, also how to go along with life with it, and it’s caused a lot of stress on my end. I mean like days of crying. I could say days of wanting to stop having to use the bathroom all the time or stop having back pain. I think it’s causing a lot of stress on my end, me and my doctors trying to figure out how to help me better than having to stress about it all the time. So, I think it’s caused a lot of stress on my end.

Several participants mentioned their mothers and other women in their families being diagnosed with endometriosis. For example, PRT3 shared her distress related to having endometriosis and hereditary concerns as follows:

> It gives me anxiety when it comes forward to it. I'm like, okay, well, let me plan this stuff around this because if I'm going to get my period, then no, I don't want to do that. And then also mentally like experiencing the miscarriage from that (endometriosis) with my other two pregnancies. It was like every day, every day, you're like checking, you know, like checking for symptoms or signs of maybe miscarrying, or things like that. And then I keep looking (endometriosis) up. Is it hereditary because my mom has it?

PRT3 also described her experience with mental illnesses by stating, "Yes, and I have been diagnosed with anxiety depression, and I'm on medication with that. But I don't know if it's related to endometriosis because I talked to a separate, you know, therapist for that." PRT6 stated, "So, I've dealt with depression at random points in my life, and I definitely feel like the pain I would experience, especially knowing, because a lot of times when I experience depression, it's because something's out of my control,"

PRT8 described her endometriosis-related mental distress. She stated, "Yes, like stress, anxiety, symptoms of depression. But that's all because a lot of endometrioses is hormonal changes and hormonal fluctuations."

Symptom Management

All eight participants responded to questions about their practices and treatments for endometriosis symptom management. Regarding symptom management, every participant used pharmaceutical, nutraceutical, or other treatment modes and techniques to manage their endometriosis symptoms. Participants reported treatments and remedies to manage their symptoms as follows (from the most used to the least used remedy):

- attending doctor visits
- using birth control pills or patches
- implementing dietary changes and exercise routines
- resting
- doing pelvic floor therapy
- overmedicating and taking pain relievers
- undergoing hormone therapy
- applying heating pads
- lying on the floor
- massaging the stomach area
- meditating
- taking soaks or hot baths
- using essential oils
- changing to natural pads

Despite the participants trying a variety of practices and treatment modalities, seven of the participants who reported having pain still reported having persistent pain even after trying to manage their symptoms. The women also noted that the pain medications were ineffective. Lastly, several reported not wanting to take birth control pills because of weight gain and mood swings. Notably, one participant mentioned that she could not stop taking birth control pills because she developed cysts on her ovaries when she stopped taking them. Also, half of the participants were recommended to have a hysterectomy as a remedy for their symptomology. This section includes participant narratives about their symptom management practices.

PRT1 described how she copes with both her mental and physical symptoms. She said the following:

> Just the home remedies, honestly. As far as depression goes, I try to spend time with my kids or do something other than that, you know? Find a stress reliever, or take a hot bath or something, but for the most part, there’s nothing really that I can do. As far as pain, I can probably take a Tylenol if I have to, but [I am] trying to avoid that as well.

Regarding managing her symptoms during the COVID-19 pandemic, PRT4 discussed the ineffectiveness of prescribed medication dosages. She shared, “So, I didn’t. I wasn’t able to manage. That’s why I started seeing a therapist.” She explained further, “I overdosed on painkillers. I took like 14 or 15 pills. That’s how I can function. Like, I wish I didn’t have to, but in a day, I’ll probably take 15 or 14 just to function.”

PRT5 described her pain management routine mentioning limited options. She stated, “Heating pads, Ibuprofen, not taking the prescribed amount, laying in the bed. That’s really it. If I’m not lying in the bed or using a heating pad or taking some medicine, there’s nothing else.”

PRT6 shared her experience with changing products. She shared, “So, I did change my pads to something that was a more natural brand, something that was supposed to be better for you," She further explained, "If I get really bad cramps, and they're not subsiding, I will still revert to my little palette on the floor that I would make. But I also try to give myself like massages in my stomach."

PRT7 expressed not having pain and other symptoms. She described her pain management technique by stating, "I would say I've managed them the same as I did pre-COVID. So just, you know, taking birth control which has really helped with alleviating the symptoms."

PRT8 listed her pain management practices. She shared, "A lot of being proactive on my own with diet, exercise, or just lifestyle changes like stretching, meditation, or, resting, really. Yes, that's about it."

Delayed Diagnosis

All eight participants responded to questions about the timing of their diagnosis and the onset of their symptoms. Six of eight participants expressed a delay in their diagnosis, with the most extended delay being for a participant who started her menstrual cycle at nine years old. She had severe pain and bleeding for many years but was diagnosed in her twenties. Delayed diagnosis was also related to the participants' level of care. However, since the diagnosis delay impacted their health and resulted in delayed treatment, I included this category under the health theme. Notably, most of the affected participants indicated that this delay in diagnosis also indicated improper care on the providers' behalf. This section reviews participants' comments related to a delayed diagnosis.

PRT1 recounted her delayed diagnosis experience with doctors in Atlanta. She shared,

> Yeah, I didn't pay attention to them. I thought they (endometriosis symptoms) were normal until they (the doctors) told me that they weren't. I did fight with the doctors a little bit at the beginning because, for some reason, doctors here in Atlanta don't believe people when they tell them things. So, they kind of thought I was over-exaggerating or something, so I had to go a little far to prove something to them.

PRT4 shared the psychological impact that the delayed diagnosis had on her. She commented as follows:

> So, it took a while because I feel like it's not like you don't tell [doctors]. Doctors brush you off. So, for a long time, I was like, "Man, this pain." Like, the pain is too much. I didn't think it was normal to have to drink 14 painkillers or that my emotions [change], like I literally lose control of my emotions.

PRT5 expressed her experience with prolonged symptomology. She stated,

> I felt like it would have to be years of complaining, like even years of showing them (doctors) the different weight gains that I've had too because I mean I've gained weight. I've lost weight, gained weight. I've had like issues of iron deficiency, issues with energy. Having to be told like, "Oh, you need to take iron pills, you need to eat more green leafy vegetables, like more liver." Things like that just because, well, I think that the two (diet and weight) kind of correlate or go hand and hand.

PRT6 had the longest diagnostic delay and was diagnosed with endometriosis in her twenties. She stated,

> It was definitely a delayed diagnosis because, like I mentioned before, my cycle started when I was nine [years old]. And since I've started my cycle, I've had a very heavy cycle, very painful periods, very painful cramping, the light headedness. Those different things, and, you know, as a kid, you don't really know that those aren't things that are supposed to happen.

PRT7 explained that she started her menstrual cycle in college but that her mother and sister started theirs at 15 or 16 years old. She reported going to the doctor at 18 years old and shared that the doctor told her that her situation was not normal. However, he did not diagnose her until after she started college.

PRT8 had over a five-year delay in her diagnosis. She expressed,

> The symptoms started, so that was probably since my first period cycle, which was about when I was 14 or 15 years old. So, it took about five years to be officially diagnosed, and I think I didn't even get my laparoscopy until I was like 21 or something. So, five plus years, I guess.

Perceived Level of Care (Pre-COVID-19)

All eight participants responded to questions about their perceived care level before the COVID-19 pandemic. Six of the eight participants reported that they did not think they received adequate medical care for endometriosis symptomology before the COVID-19 pandemic. Two participants stated that they did have a good level of care before the COVID-19 pandemic. However, the majority of participants made comments reflecting negative sentiments regarding their perception of care before the pandemic. This section reviews participants' comments related to this topic.

When questioning PRT1 regarding her perception related to the quality of care she received before the pandemic, she remarked,

> Before [COVID-19]? No, that was through the period I feel like I wasn't being listened to. Things have seemed to hit a little harder, a little stronger since I had my last baby for some reason, and I'm thinking because of the [health] complications really.

PRT2 described her pre-COVID-19 care as less than favorable. She explained, "I think before COVID, no, because I think it (endometriosis) was something that a lot of people didn't know about, especially male doctors."

PRT3 emphasized treatment as her reason for receiving sub-par care before the pandemic. She stated,

> Before COVID-19, I would say no. Only because, like I was stating before, their go-to is kind of just like, you know, they prescribe you pain medication. That's it. That's what was happening. Before COVID-19, I would say no.

PRT5 described the ineffectiveness of treatment for endometriosis pain during the COVID-19 pandemic. She shared,

> I would say no because I feel like Tylenol does not do the trick. So, there has to be, well, excuse me, Ibuprofen does not do the trick. It has to be like another means of treating something. Like I feel like that's just like putting a band-aid on a wound, like it's not the same. So, no.

PRT6 responded to this subject similarly to other participants. She addressed the ineffectiveness of treatment as follows:

> I think I would say no just because I think for so long the birth control pills didn't work. They didn't really have an effect, or at least it wasn't noticeable for me. So, I felt like I was just taking these pills all the time and didn't really understand why I was taking them.

PRT8 described her feelings of inadequate treatment pre-COVID. She explained,

> No, because like I was saying before, I've made the mistake of going to an OB/GYN instead of like specialists, like endometriosis specialists. So, I feel like before COVID, we were still kind of searching for the right care.

Perceived Level of Care (During COVID-19)

All eight participants responded to questions about their perceived care level during the COVID-19 pandemic. Five of the eight participants felt they received better or the same level of care during the COVID-19 pandemic than before. Of those five participants, two mentioned receiving better care during the COVID-19 pandemic due to the uniqueness of their situations. One participant attributed receiving better care during the pandemic to requiring special attention due to multimorbidity and contracting COVID-19 while hospitals were excessively staffed. The other participant attributed her perception of receiving a higher level of care to her decision to change providers because of her pregnancy; she began treatment with a midwife and a doula. Only three participants indicated they felt they received the same or a lower care level.

Moreover, five of eight participants made 13 references regarding their being inconvenienced by limited access to face-to-face doctor's appointments, long emergency room waits, and the inability to make appointments. Notably, most participants expressed that they engaged in self-care practices while confined to their homes and facing pandemic restrictions during the COVID-19 pandemic, self-managing their endometriosis symptoms at home. This section will address several participant narratives for those who endorsed receiving adequate care during the COVID-19 pandemic.

PRT2 attributed receiving better care to multimorbidity and contracting COVID-19. She said that because hospitals were fully staffed during the height of the pandemic, she received care for her COVID-19 symptoms, thoracic endometriosis, heart condition, and asthma. She stated,

> They were giving me all these medications because they didn't really understand what I had, and I think when, like I said, when COVID-19 came on hand, they did more tests and figured out, okay, she has thoracic endometriosis, like it's affecting her lungs; it's affecting her tremendously. Like we need to give her something other than that (pain medication).

PRT3 discussed limited doctor appointment availability. She explained,

> So, that has been kind of, you know, just a whole different experience in itself with going to doctors and sometimes there was one point when doctors weren't really seeing anybody unless you had COVID symptoms. So, that was kind of rough at the beginning, but I feel like It's evened out. It's gotten better.

PRT3 also explained that she felt her care was better during the COVID-19 pandemic because she changed her provider from a traditional physician to a doula and a midwife. She described her experience as follows:

> Now during [COVID-19], I would say, yes [the care was better]. Because when I was pregnant, I stopped going to a gynecologist because they were, you know, giving me the same [medicinal treatment], just take this, take this and that. And I actually found a midwife and a doula. Those are the only ones that I really feel like have, you know, kind of cared for me more and tried to see like what can make me more comfortable. Or [find out] what's going on.

PRT4 expressed having mood swings during the COVID-19 pandemic that resulted in her seeking psychological care. She explained,

> I think I did [have adequate care]. I think that, for example, with the mood swings and sometimes I get angry, like all that stuff. She (the doctor) suggested that I see a therapist. And I started seeing a Black one as well. So, she understood that pain and we were able to talk about a lot of things. So sometimes now, dealing with my mood swings, when I feel like, "Hey, I'm not really myself" or "It's someone else," you know. Sometimes when I feel all that, I don't drink [alcohol] at all because I know that heightens the situation, for example. So, I do think she's given me the tools and she's given me the support that I need to help, that can help me.

PRT8 stated that health care can be improved regardless of being in the COVID-19 pandemic environment. She shared,

> Well, I just think the only thing that COVID really affected is probably the scheduling and the accessibility to in-person appointments, which affects like your ability to really communicate what's going on with your body because I think it's really hard to do something virtually when it's a very physical disease. So, yes, that's the only thing that I think COVID-19 affected during it. But otherwise, I'd say the care still needs a lot of work, regardless.

Life With Endometriosis

This theme is related to how the participants viewed life with endometriosis, which was an underlying theme in all of the interview questions in one regard or another. It includes three subthemes: the nature of endometriosis, the impact of endometriosis on the participants' lives, and the participants' support systems. During the interview, participants shared one-word describing the nature of living with endometriosis, the impact of endometriosis on various aspects of their lives, and the impact of having or lacking a support system while coping with endometriosis symptoms.

Nature of Endometriosis

All eight participants responded to a question describing how living with endometriosis makes them feel using one word. The words that participants used to describe endometriosis were: "painful," "powerful," "handicapped," "difficult," "Eve," "hell," "normal," and "misunderstood." Notably, most women thought hard and struggled to find only one word to describe the intrusive and encumbering disease. Impactful and original statements supporting the rationale for their words of choice are included in this section for the six participants who provided explanations.

PRT1 described life with endometriosis as “painful.” She stated,

> One word. Oh, man, that’s what makes it hard. I’m just going to say painful; I’m assuming. I don’t know. I have so many words, and you say one word. That just threw me for a loop because I have so many words for it. I’m going to have to go with painful on this one.

PRT2 shared that life with endometriosis has been “powerful.” She described her experience with the disease as follows:

> Powerful. I think that word kind of, for me, can be used in different ways. Kind of like one way it can be used, as I know that I can get through it. And I kind of use the word powerful to tell me that I’m a powerful human being. But I think it also can be used as it’s such a complex, challenging, and powerful illness that some people can’t begin to understand. But I know I understand it, and I know what I’m going through. Therefore, I kind of consider myself powerful for being able to go through it.

PRT3 deliberately chose and explained her word choice, deciding on the word “handicapped.” She recounted,

> I’m really trying to find a good word. The word like “handicapped” comes to mind. Like handicapped in a sense like, you know, how sometimes people are handicapped like they can’t do certain activities, or they have to take different precautions. So, I would say handicapped in the sense of like whenever you know your period is coming on, it kind of handicaps what you can do, or, you know, whether you’re planning a trip. Or a definite flag is handicapped in my sex. Like

> it can’t just be like spur of the moment type thing. It gets like, you know, you got to take all of these precautions even when it comes to having children and stuff. But yeah, I would say handicapped.

PRT4 candidly described endometriosis as “Eve.” She justified her response by stating,

> Eve. Yes, because I get so upset because I’m like, if she hadn’t eaten the apple, then we wouldn’t be suffering all this. Yes, so whenever I’m on my period, I think of that specific point in the garden. Yes, why do we have to go through this when the men don’t?

PRT7 responded that her life with endometriosis has been “normal.” She shared,

> Hmm! I would say normal. Yeah, I would say normal because it hasn’t, I mean, aside from taking birth control, it hasn’t really changed my life or affected my life in a negative way.

PRT8 described endometriosis as being a “misunderstood” disease. She explained her word choice as follows:

> “Misunderstood” would probably be the word I choose because I feel like it’s a disease so misunderstood by everyone. I mean scientists, doctors, friends, family, I think it’s really hard to really vocalize just how this disease affects you because it’s so complex that you just sometimes don’t even know how it’s affecting you until, like, you reflect on it. So, I feel like it’s often misunderstood by myself sometimes. So, I think it’s just a grossly misunderstood disease.

Impact of Endometriosis on the Women’s Lives

All eight participants responded to questions about how endometriosis impacted their lives. Participants discussed how being a Black woman and having endometriosis during the COVID-19 pandemic had impacted them. However, that topic will be discussed under another theme, the nature of being a Black woman in the United States. Seven participants expressed that endometriosis had impacted their lives in multiple areas and their overall quality of life. PRT7, the only married participant, explained that her primary concern related to having endometriosis was fertility and childbearing; she noted that she and her husband wanted to have a baby soon. The women mentioned that endometriosis had impacted their lives in many areas, including day-to-day activities or general daily life; work and academic life; income; sex life and relationships; mental health (many were diagnosed with anxiety and depression); and challenges with getting proper care, having a family, or fertility and childbearing. This section provides self-reported, detailed accounts of how this disease impacted the participants’ lives.

PRT1 discussed that endometriosis interfered with her aspirations of having children and a family. She expressed,

> Having a family. I’ve always wanted a lot of kids, and you know I got two. But I want more, especially I want a little girl, and it’s just I’m getting older. I’m not getting any younger, and right now, I don’t think that’s going to move too quickly. It’s definitely impacted me have having dreams of the family. Definitely thankful for the ones I got.

PRT2 discussed how her endometriosis symptoms impacted her work life. She explained,

> I would say, probably work life. You know, even though I'm a student, I do work. I plan on cutting down hours, but I stand a long period of time at work because I have like a position to where I'm helping people all the time. So, but the symptom of chronic back pain it's all the time. It's all the time constantly hurting me, especially if I'm on my period. Work makes it harder for me to even stand those long periods of time, and even going to work period. Like the other day, like a week ago, I had to visit OB/GYN because I was having chronic, really bad pain. And I was like, okay, I can go to work and then I realize, I'm like, Yeah, no, I have to call in. Like it affects my work life tremendously because I'm missing out on that pay when I have to pay tuition and bills. Like it affects my work life because I'm missing all these days that I could be having pay. But it's like my health comes first before I decide to even do other things.

PRT3 explained how endometriosis has affected her work life and childbearing. She shared,

> I will say, yeah, it's definitely impacted [my life], as far as work goes, I mean, before having my children. I breastfeed, so I haven't been having a menstrual cycle. But before being pregnant, just like how I would have to take off of school. And there were certain times where I just couldn't, you know, work for that day, and I'll end up having to take off of work. So, I would say it affected my work, and it affected also having children because I did suffer from one miscarriage.

PRT4 shared similar concerns as PRT3 regarding childbearing. She said that endometriosis had impacted her life as follows:

> Oh, yeah, I think definitely, work and definitely I kind of have a little anxiety with childbearing because I know that my time, my biological clock is ticking in itself. And I'm single and I want to have children, and I'm hoping that this (having endometriosis) won't affected it. So, I'm a little bit anxious because of all that. So, I guess, dating. Yeah, I would say dating, work, and life.

PRT5 shared her challenges with painful periods. She stated,

> For me, I feel like it has impacted, one, like sometimes my day-to-day activities, like during my menstrual cycle. Even leading up to the menstrual cycle, that's how I know it's coming. I know it's coming because I could feel the pain. So, I can start to feel that. I feel like my sex life is affected by it. Definitely doing sexual activities, and, I will want to say, like day-to-day activities leading up to like a cycle, or even after a cycle sometimes. I think I still feel the aftereffects like between, leading up to the cycle, the cycle, and the end [of the cycle]. I feel like you can feel it, like you can feel something is not right in your body. Yeah, not just ovulating like they'll say, because I was told before, too, like sometimes when your body's getting prepared to ovulate, you experience pains. Negative, that's not, no. That's not it at all. That's not the same, not the same.

PRT6 recounted her experience with endometriosis and described it as painful and disruptive to her life. She stated,

> Yeah so, I definitely feel like it's impacted, at times, just my general daily life; the things that I can do and when I can do them. Because my cycle is so heavy, like, physical activity, typically that week I don't do, I can't do a lot. Because my cycle would be heavy, I wouldn't be able to, you know, do as much as I normally would. And then my cramps, because when they start, it's not like hey, oh, I cramp for a little bit, then I'm fine or it's not that bad. It's really intense to the point where I don't, I can't really go anywhere, I can't do things, I have to stop what I'm doing and kind of pause and breathe through it, wait for it to pass. So, my daily life at times, when my cycle starts, I definitely feel it's impacted even like relationships. So, for me, sex can be painful at times. And I guess that was a symptom I should have mentioned earlier. That sex can be painful. And so, like knowing that for a long time, that was a point of shame for me because I didn't understand why, like, why these things are happening.

PRT7 described her challenges related to infertility. She stated,

> So, when I was 33, four years ago is when my husband and I started trying [to conceive], and we did like a bunch of labs and workups, and that's where the ultrasound came into play. So, infertility is something that I'm affected with, and my doctor said it's related to my endometriosis. So yeah, I am affected by infertility, unfortunately.

PRT8 discussed her experience living with endometriosis, explaining that it had impacted every area of her life. She shared,

> Well, I feel like it’s pretty much impacted like every aspect of my life, physically, mentally. I struggle sometimes with getting the proper care. So, living with endometriosis is a little harder because it’s a daily thing. It doesn’t really go away. I think the myth is that endometriosis is just around your cycle, or you struggle with it just around your cycle. But it seems it’s a daily thing. It’s like a daily struggle for people with endometriosis. So, I’d say it’s affected like every aspect [of life]. Like mentally, I struggle, like I said, with depression and anxiety, and hormone changes cause a lot of those things. Hormone changes also cause a lot of fatigue or like chronic pain or inflammation. I mean they all kind of like play off of each other, too. So, yes, I feel like it has a cyclical effect on your life.

Support System

Most participants mentioned the importance of being supported by medical and mental health providers, family, friends, and partners. The word “support” surfaced thirty times and related to multiple questions. Also, regarding support from various sources, most participants highlighted the importance of being heard or listened to by others. Therefore, I identified the need for a support system as a category under this theme. Several participants expressed feeling misunderstood, isolated, or shut down by their partners. Statements expressing how participants perceived the importance of having a support system are described in this section.

Regarding the need for support, PRT1 mentioned that she did not have enough support from people because she felt like they did not know that she was in pain. She explained that she did discuss her personal business with others. She also expressed not having sufficient support from her doctor.

PRT4 discussed receiving the tools and support that she needed from her new therapist and how it helped her to cope with her mood swings. However, she indicated that she did have much support in her workplace.

PRT6 explained that she had a support system but would have liked to have better support as a college student in the academic setting. She shared,

> I definitely feel like I need [a support system]. I have a support system, you know, my parents, my best friend. I have another really close friend; she lives in New York. They're all super supportive, super, yeah, supportive. I definitely need to find my group, though. [One] that's able to be supportive and understand what I'm going through right now because I'm a first generation [college student]. My parents, they have no clue what I'm doing.

PRT8 expressed that a lot of people really don't understand the nature of endometriosis. She stated that "it's still a mystery" and, consequently "a lot of people really don't know how to react when it comes to support in that way." PRT8 also expressed,

> I've joined support groups online and I've researched different events. In a way, a lot of the times it feels in these support groups, it feels like we're the only ones we have. Like we only have each other because it's, like I was saying, it's really hard to understand this disease unless you struggle with it. A lot of the times I lean on support groups, or I'll feel the need to like offer any information or any remedies,

> or any sort of things that might work for me work, any habits that might work for me or any new findings that I’ve researched. So, yeah.

PRT8 had surgery during the COVID-19 pandemic and shared her experience in the following narrative:

> Another thing that I guess, during COVID-19, I think it was 2020, when I had my second or third surgery. Oh, I think it was my third. And I had it in Baltimore, I think with a specialist. And the hardest part about having surgery during COVID was that you’re not allowed to have any visitors with you. So, a lot of that support that is already kind of thin and already kind of not there, or non-existent in some cases, is even shortened by like not having, you know, you not being able to bring anybody back with you. Or no one can come in with you to have that like physical support there. A lot of the surgeries with the doctors was kind of like, almost it felt a little like distant and impersonal because you couldn’t really see them in person as much because COVID restricted that. You would have to either see them virtually or just talk to them over the phone, which can kind of be a little unsettling and discomforting when you don’t have that personal connection with someone who is, you know, doing surgery on your body. No matter how small, no matter how big, there’s an anxiety there with just, you know, anyone going under surgery. And so having that comfort to be face-to-face with your doctor was almost non-existent. It was very impersonal, very like virtual, and very kind of like matter-of-fact. You know, just step to step to step, and was like no access to support there, especially emotionally. So yeah, I’d say that was like a huge thing,

> was that a lot of that already thin support got even thinner with COVID. And I think a lot of, a huge part of having endo is like the emotional portion of it because it affects a lot of how you live, how you perceive things. So, I think with already that limited accessibility to support and limited education on mental health, I feel like it probably made things even more complex because it's like there's no support on any level.

U. S. Health Care System

All participants answered the question regarding the overall quality of their medical and mental health care. Of eight participants, six indicated that they think the quality of the U.S. health care system needs improvement. Two participants stated that they were satisfied with their health care. Notably, one of those participants did not have chronic pain associated with endometriosis and only needed birth control to help with her irregular periods. The other participant expressed that she felt that her doctors were doing the best that they could in helping her where she was regarding her illnesses. Four participants cited the lack of available resources, funding, and research for endometriosis and those who suffer from it. Also, several participants referenced insufficient insurance coverage, insurance lapses, and other insurance issues. Although participants also articulated that doctors needed to take the time to listen to their patients, this topic is discussed under a different subtheme within this theme related to the quality of provider care. This section reveals participants' perceptions related to insurance coverage, endometriosis resources and research, and participants' positions regarding the overall quality of provider care.

Insurance Coverage

As mentioned above, four participants discussed their insurance shortcomings multiple times. Although I did not ask a specific question regarding the quality of the participants' insurance, they often referenced how their insurance coverage deficits affected their health care. This section reviews participants' comments related to their perceptions about insurance coverage in the U.S. health care system.

PRT1 remarked about the impersonal nature of insurance plans. She shared, "I feel like they don't have a lot of empathy. Honestly, it's just like they want to swipe the Medicaid or Medicare card and go about their business. Like, that's just how I feel."

PRT3 discussed insurance plan limitations. She expressed, "Or I'm like is there somewhere where I can meet you guys face-to-face. But it's because we have that low-income insurance, so they don't. You know they don't allow that I guess," She also stated,

> Let's say the most challenging thing would just be actually getting into the doctors because, well from one, I have to go with certain doctors that take my insurance, and then a lot of times they're in like little office buildings, not like an actual clinic.

PRT3 also shared,

> One of the main ways I would say how [my insurance plan can be improved] is because the one [mental health plan] that I have from my insurance, they don't offer like in person. The medical one they do, but only when they have appointments available. So, I feel that [health care quality] can be improved

> maybe by not basing it on income, but kind of making everybody feel like they matter or they're important, and we should all be able to get, you know, the care that we need.

PRT5 explained her challenges related to the affordability of health care insurance. She shared her story as follows:

> For me sometimes it's related to like the costs. So, a lot of times, you know, of course, insurance don't cover all this, and a lot of times you try to figure out who's going to pay that co-pay. Sometimes you do have to reach like a certain deductible, well, a certain limit before. Yeah, so I mean honestly sometimes it's the pay. Like, I am 32, while I am like dating someone, I am in like a single income household. I do own a home. I have a car. I have bills. So, I mean, in essence, it really is the money. Yes, sometimes they can nickel and dime you like they don't see it as a priority either.

PRT5 also candidly expressed her feelings about the U.S. health care system, speaking on intersectionality and what Black women cope with daily. She stated,

> So, I think another thing I could talk about, too, is the fact that all of these people who are making laws have no idea what we go through in a day. And it's like I should have put a budget, an extra budget, for myself to suit the health care that I need when I think this should be free. It's because not everyone goes through what we go through.

PRT6 explained her experience with health insurance as follows, "I've had to kind of plan ahead for things to make sure I'm able to either buy my birth control pills without my insurance or I had insurance to get it," Also, PRT6 could not afford mental health care, despite needing it, and stated, "It was just always in my mind like, okay, when I have insurance, I'm going back to therapy. That was always my plan." Regarding interruptions in her insurance coverage, PRT6 also stated,

> So, because of COVID-19, I had periods, and also just because of my timing with ending my master's program, of going into the workforce for a little bit, having these interruptions in my insurance because of my age, and aging out of being able to use my parents' insurance, I've had lapses in my insurance (. …) So, during COVID, getting the new birth control pills, making sure that if I know there's a lapse in my insurance, [I ensure] that I'm addressing it before it happens so that I can have a supply before I need it.

Resources and Research

As mentioned above, all participants answered the question regarding the overall quality of their medical and mental health care. Although I did not ask them questions about resources and research related to endometriosis care and endometriosis, several participants mentioned limited research funding, limited resources, and the unawareness of or inaccessibility to resources for endometriosis. Also, all but one of the women expressed how misunderstanding endometriosis and ineffective treatments adversely impact their lives as women and as Black women. This section includes statements made by several participants regarding their perceptions about limited endometriosis research and resources.

PRT2 discussed the disconnect in medication treatments for endometriosis. She shared her sentiments as follows:

> I feel like there's a big gap. And I've been noticing this [phenomenon]. And this is not just with endometriosis. I think it's just the OB/GYN care period. But I feel like there's a big gap in the medications. I feel like sometimes they might throw out a medication, but not necessarily for that (endometriosis).

PRT4 discussed this topic as follows: "Yeah, I think definitely, by studies like this that are talking about like going further and talking to people. And being able to find out, hey, like how do you function in a day because people think it's normal."

PRT8 expressed the most concerns related to research and resource deficits for American Black women who have endometriosis. She shared her perspective on research gaps by stating, "I feel like either way, COVID or not, the funding for endometriosis and the research, and really just the awareness in general, is lacking. So, it's really hard to get help no matter what." She also commented, "I feel like the resources aren't communicated well to patients with endometriosis. Like, I feel like they focus on the physicality of the disease instead of like the actual holistic effect the disease has on a person," PRT8 also remarked, "I don't think that there has been much talk or like awareness of accessibility to like mental health resources, or any of that." She explained, "They (doctors) don't have the resources to support you. A lot of doctors aren't really there to support you in being vulnerable. They're just kind of there to treat you as a patient." Lastly, PRT8 shared,

> So yeah, it does feel like a lot of the weight falls on me and other Black women to really educate us like, educate ourselves and educate each other because a lot of the times these doctors will deny us the right to help, or education or resources or accessibility to these resources (. …) So, a lot of doctors aren't as proactive as they could be. So, yeah, I just think that there's like a huge lack in funding and resources to really get the holistic care that a lot of patients need because endometriosis doesn't just affect one thing.

Overall Quality of Provider Care

The quality of care the participants received while having endometriosis symptoms during the COVID-19 pandemic is a core topic in this study. Concerning participants' feelings about the quality of their doctor's care, they commented on the doctor's competence, empathy, level of care, and treatment. Most participants often felt their doctors did not listen to them, validate their pain and other symptoms, or provide effective treatments. All eight participants indicated that their primary care doctors did not inquire about their mental health and did not refer them for mental health support unless they mentioned the topic. Although six participants expressed negative feelings and attitudes towards their doctor's level and quality of care, four have found new doctors; one changed her care to a doula and a midwife. Notably, several changed to providers who were women of color.

The women often expressed that their doctors seemed incompetent or had insufficient or inaccurate knowledge about endometriosis, treatment, and resources. The women also said their doctors did not provide emotional support, appearing uncompassionate and lacking empathy. One participant mentioned that her doctor's misinformation caused her more harm and left her with excessive scarring. All but two participants expressed that their doctors have never inquired about their mental anguish or mental distress related to their endometriosis symptoms. One of these two participants indicated that her provider addressed her mental health concerns due to her having complications related to contracting COVID-19 while dealing with multimorbidity. However, she had to tell the provider about her anxiety and depression before he helped her with her mental health needs. The other participant explained that her previous doctor did not address her mental health needs; however, her doula and midwife did address them. As shared above, at various point during the interviews, six participants expressed adverse sentiments regarding the quality of their care. This section includes many of the comments on this topic.

PRT1 talked through ways that her care could improve. She shared,

> [It] definitely can be improved always. I thought these doctors need to take their time with their patients. They need to listen to their patients. They need to be honest more than anything because if they don't know, it's okay to say you don't know. I understand you went to school for this long. Maybe you just don't remember, you know, maybe they messed up and did teach them, you know, just always something behind everything. So just be honest, like I've had a doctor one time that actually told me, "Look, I don't know what was wrong with you." But they went a mile ahead and sent me to a specialist. Just the small things count. First of all, if you're going to be a doctor, your number one thing is you need to

> listen and be patient. That’s just one. And I feel like a lot of the doctors here lack that.

PRT1 also described her experiences with a health care provider. She remarked,

> Like pushy. Like I was telling, for example, partnering my last baby, my OB/GYN was a male, and I kept telling him something’s wrong. You know having all these symptoms a little too early. I’m not even halfway through my pregnancy. “Oh, you’re fine! Oh, you’re fine, like Oh, you’re fine” and then they come to find out no, I wasn’t fine. I ended up needing to have more than one shot a week. They ended up having to do test on me. It was so many tests I can’t remember like I was getting the test done; I don’t even know what the tests were for. And actually, when I did switch away from him and I chose not to see him no more, that’s when they actually told me that I had gestational diabetes. So, I just felt like he was being too pushy. He was too high up on his horse and he would not listen.

PRT2 shared her experience with providers’ lack of understanding as follows:

> But I think it was the lack of understanding of what I had that I was constantly like saying “I’m in pain, I’m in pain,” and you know people tend to give you medicine when you’re in pain. They don’t want to look into what you had, and I think that’s what they were doing to me.

PRT2 also discussed providers prescribing ineffective treatment and shared,

> I feel like they could be better with the medications and the treatment honestly. They seem to do the testing and all that fine, but when it comes down to the nitty

> gritty of the medications and the treatment that they’re going to offer, I feel like it just goes out window.

PRT5 summarized her experience with providers invalidating her symptoms and concerns as,

> I felt like I had to do like a lot of complaining. I felt like people didn’t believe me because they thought like, “Oh, yeah, well she’s a child. Maybe she doesn’t know what she’s feeling.” It wasn’t until like I told you, I literally had to like take pictures so people can get the gist of what I’m saying. I don’t think they understood it until I got like this most recent physician.

PRT5 shared similar concerns by stating, “I felt like you know, she was just not really listening. I felt like she would appear compassionate, but the empathy was not there.” She mentioned the inefficacy of prescribed medications and discussed her feelings related to providers not listing to her in the following statement:

> Yes, by actually having people actually listen, and not only just like diagnose you with stuff. But like do things to kind of like combat it. Like do things to like alleviate pain, or, you know, alleviate those stressors or things like that, like do something to help the situation. I mean you just don’t get a lot of good help nowadays, so.

PRT6 discussed not understanding her medical condition by stating, “So, the things I was experiencing that I needed to stop, in the name, it’s not telling me what it’s going to do, and they never gave me an actual explanation.” Regarding the ineffectiveness of her pain medication, she shared,

> A lot of times, I just lay on the floor and kind of hope for the best, which is a horrible solution, but it's kind of, it's what I had so I would just hope for the best. But yeah, I'd never really felt like they (pain medications) helped with the amount of pain I was experiencing.

PRT6 explained that her doctor never educated her regarding consuming birth control pills as endometriosis treatment in the following statement:

> And it was just kind of like "Oh, well, let's put you on birth control." And I'm still, you know, a teenager. I'm not really understanding why I need to be put on birth control. Because it was never really explained like we believe this is possibly what it could be or these are the symptoms you have, this is how it's going to help. It was never explained to me (. …) So, in a way, I feel like she understands, but the same time I don't necessarily feel completely confident in the treatment. Because I know for me, I've definitely had a lot of questions for her because it is a concern for me, not knowing what extent I could have it.

PRT6 elaborated on her discussion about birth control pills being an ineffective treatment as follows:

> I think for so long the birth control pills didn't work. They didn't really have an effect or at least it wasn't noticeable for me. So, I felt like I was just taking these pills all the time and didn't really understand why I was taking them.

PRT6 also discussed her feelings related to her perceived quality of care as follows:

> So, being able to take that and listen to their patients and actually be there and have time. Don't rush them through because you've overbooked yourself, or

> you're trying to get in as many people as possible. Make sure they have time to talk to you about what they're experiencing and why they might be experiencing it, and work with them to figure out like okay, well, what's going to be the best solution for you? Because what works for one person is not going to work for the other. So yeah, I think that's honestly the best way to make things a lot more equitable is improvement in treatment here.

PRT7 attributed her delayed diagnosis to doctors misunderstanding endometriosis. She shared,

> I feel like they (doctors) don't understand because it took so long for it to be diagnosed. Like I've always had irregular periods, and they just said, you know, they never really gave me a reason why until, you know, relatively recently.

PRT8 reflected on her experience of having to do her own research and stated,

> Yeah, I feel like a lot of the journey with endometriosis is having to do your own research because a lot of the times doctors won't, their overlook things so their maybe not hear you on certain concerns. And so, it's really important to be on top of your own health.

PRT8 shared her thoughts related to providers not taking endometriosis seriously as follows:

> Yeah, I mean I'd say so. But also, like I said, I think that the disease itself is kind of still a mystery to a lot of doctors. Because it, I mean, it travels. It travels, and then can travel to the brain. I mean it's just a very like complex disease like I said, and you never know really, until like the symptoms arise which at that point it's

> kind of like it’s already happening (. …) It’s not just during your period and it’s not just located to the uterus or your ovaries. It travels. For me is affected like different organs outside of my reproductive organs. So, it’s a, for lack of better word, a cancerous disease, and a lot of doctors don’t treat it as serious as they should until it’s too late.

PRT8 described a situation related to misinformation offered by her provider as follows,

> One of the first things I heard from a doctor was that endometriosis was probably not a possibility for me because it was mainly a disease seen in White women. And to hear that from a doctor and then find out almost like a few months later that I actually do have endometriosis is grossly irresponsible.

PRT8 further detailed her experience with doctors’ surgical treatment as follows:

> So, they’ve done like surgeries like ablations which is like if you really research like ways to like alleviate it (endometriosis), that’s like the number one to not do because it causes more scaring, more inflammation, and more pain.

Nature of Being a Black Woman in the United States

All participants answered the questions regarding the SBWS and the nature of being a Black woman in the U.S. health care system. While answering these questions, a new subject arose: the intersectional nature of being a Black woman in the workplace and other settings. This theme discusses the participants’ responses to questions about the SBWS and what it means to be a Black woman in health care and other settings. The participants mentioned modeling their mothers and being parentified at young ages because their parents needed assistance or were ill. The women also mentioned having to be strong in the presence of their children and significant others or when working in a male-dominated workplace.

SBWS

As explained earlier in the study, the SBWS is a Black feminist theory with ideologies providing a context that addresses how intersectionality might affect Black women's experiences with doctors and other health care workers and their approach to and perceptions regarding treatment. The SBWS is related to racial disparities and adverse psychological effects in the participant population. This section addresses the participant responses to the five questions regarding the following the SBWS subscales: Obligation to present an image of strength, obligation to suppress emotions, resistance to vulnerability, intense motivation to succeed, and obligation to help others (Allen et al., 2019). All participants answered the questions related to this category. Participants' narratives about the SBWS are included in this section.

Obligation to Present an Image of Strength. All participants answered the question related to their proneness to presenting an image of strength. All eight participants indicated that they felt obligated to display an image of strength in various settings. The participants made impactful statements related to this topic.

PRT1 shared her experience with presenting an image of strength when having endometriosis pain. She commented as follows:

> So, I mean yes, it's a little hard sometimes because I don't want anybody in my business, you know. Sometimes it'd be really painful and I have to cry. I don't want to cry in front of people. And it's definitely hard around my kids because if

they see me crying, they go, “Mommy, what’s wrong?” Like they don’t understand. So, I feel like what’s the point of explaining?

PRT2 discussed her history of appearing strong like her mother. She explained,

But I think a lot of times when I was going through the pains I would put on a strong face, so people wouldn’t know what I was going through, so they wouldn’t ask questions (. …) So, I think that experience of taking care of my mother kind of taught me strong faces are what get you through life rather than asking for help.”

PRT3 recounted modeling her mother’s image of strength. She shared,

The reason I’m like that is just for one I think I was just raised like that, like seeing my mom like that. Because my mom has four children, but she didn’t get married until I was like 13 or 14, so I always just saw her you know. And with my children I work full time, and I work from home. But then I also take care of both of my kids, but myself, too, because their dad is at work all day. So, it’s like even if I’m not feeling well, or something like that, you know. I have to get up, and you know cook, clean, take care of them, and make sure they’re okay or anything. And then, when my boyfriend comes home, I don’t want to be like, you know, where it’s like, “Oh, my God, my stomach’s having pain” or something like that. He’s just come home so I’m not trying to dump all my problems on him. And then I always just think, like, “Okay, my mom was able to do it, so I should be able to do it.” So, then I feel like I always have to, yeah, just be okay.

PRT4 explained how her mother endorsed her presenting an image of strength. She explained as follows:

> I, definitely as a Black woman, I think that is an obvious yes. I think you know, no, because I do think that, like even like when I was telling my mom initially that my period was not whatever was not normal, she would say, "No, Black women are used to this," like we are used to being laborers.

PRT5 shared her challenges with presenting an image of strength at work. She stated,

> I would say at work only because I do work in a place where I am the only person of color. So sometimes it's kind of hard to like fully express yourself if you're going through pain. So, a lot of times like when I'm experiencing those pains, I'm a lot more closed off. I'm a lot more you know to myself. I don't really want to like engage or anything and try to like sit still or sit in like one spot so you're not, you know, doing too much moving like during your cycle. So, you know you're fine. I do feel like you do have to put on like a brave face when you're in like a lot of pain, especially at work.

PRT6 expressed her awareness of her internalization of the SBWS behaviors as follows:

> Oh, yes, oh, definitely. I definitely have that, the strong Black woman schema type of mentality. Got it from my mom and my granny like, you know, it's passed down; it's what's expected. But also, thinking of the settings that I'm in, I'm a first-generation college student. So being in these different settings, these are

> places, and I’m typically the only Black woman or sometimes the only Black person. So, in these settings I don’t want to. I never appear like I don’t know what I’m doing, I don’t know why I’m there, or like I’m in pain when I’m in pain. And so, like I mentioned before, if I’m somewhere and I need to give a presentation, I’m always cognizant about like what’s going to happen when I have a really bad cramp because I don’t, you know, I don’t want to show that I’m in pain right now and then have to explain why I’m in pain and to give me a moment. And so, it’s definitely something that’s a part of me when I go places. When I do things, I’m very cautious about what I present and how I present.

Regarding presenting an image of strength, PRT7 attributed her strong appearance to her role as a leader at work. She remarked, “Yeah, yes. I would say, yeah, I do feel like I need to present myself as a person of strength just because of my job. I’m in management. So, I’d say yes.”

PRT8 explained her perspective on presenting an image of strength. She shared,

> So, yeah, a lot of the times you do have to put on a facade of “I’m okay,” or “I don’t need help,” or “I don’t need time to rest” because it is still such a mystery to so many people, and still so many people on the street really don’t even know what it is or they can’t even tell you what causes it.

Obligation to Suppress Emotions. All participants answered the question about feeling obligated to suppress their emotions. Six of the eight participants said they felt obligated to suppress their emotions. Two of the participants indicated that they used to hide their feelings but were trying to improve this behavior. The participants' responses to questions related to this topic are included in this section.

PRT1 described her feelings about suppressing her emotions around her children. She stated,

> Yeah, especially around my kids or in public. I not going to lie. When that time comes around, I'm pretty much out, like I don't even want to go to the grocery store. I'm just a very private person. I don't want to. It just depends on who it is. Like as far as my kids go, I don't want them to see me upset. That makes them upset when they ask those questions and even if I did answer, they would not know what I'm talking about. So, what's the point? I mean then as far as outsiders, who wants to sit and cry in front of somebody? I mean, yeah. I'm going to try to hold back my emotions, my feelings or whatever. I'm trying to hold it back, so I can only get so far. Now if it gets too bad, you know, I'll have to let it go. But I'll just try to keep it to myself.

PRT2 reported her history of suppressing her emotions. She shared the following:

> So, currently I kind of stopped suppressing them. I kind of just let them flow. I recently decided to, you know, acknowledge that I needed some kind of form of therapy, whether that'd be mental therapy or physical therapy. Since my mom has been dead for 4 months, I've kind of gotten a lot of clarity on certain things and It's kind of made me realize that I need to ask for help and acknowledge certain things that I'm going through rather than keeping them bottled up or keeping them put down.

PRT3 expressed that she lacked support at home and in other settings. She described her experience with suppressing her emotions in the following statement:

> But I’ve explained to her (the psychiatrist) that I do feel like that because my partner isn’t really, well not even just him, really just in the African American culture alone like depression and anxiety and stuff are kind of looked at like you know like “Oh, it’s just a phase or tough it up and stuff,” and I try to open up to him and tell him about it and he’s like, “It’s just a mental thing like, you know just tell yourself don’t feel that way.” And then I try to tell people, you know, it’s not that easy. But once you open up about how you’re struggling mentally and people shut you down like that, it makes you, you know, I just don’t say anything else, like If I’m struggling mentally sometimes, I’ll write it down and just throw it away, or I’ll type it out in my phone how I’m feeling and then just delete it. You know, I don’t open up and tell anybody anything because I don’t want to be judged. Sometimes, you know I’ve heard people like, “Okay, well, did you you’re your medicine because you’re tripping,” and it’s like I’m not tripping. I’m just, you know, anxiety just creeps up sometimes. So, I definitely feel like I have to keep my emotions and feelings just like leveled, I guess. I don’t know.

PRT4 bluntly explained her rationale for suppressing her emotions. She stated, “Yes, because I don’t want to be labeled an angry Black woman.”

When responding to this question, PRT5 shared her challenges with emotional regulation. She stated,

> I would say yes, because typically people always see me as like, you know, the happy-go-lucky, the jolly, optimistic type of person. But then when I'm experiencing like those things like I'm not in a good space, like I could go from 0 to a 1,000 like really quick. Like the thing is it's not me, I just feel like it's the pain, and like I feel like nothing is happening fast. Like even when I take Ibuprofen, I feel like it's not happening fast enough, so I just like keep wanting to consume them until I just like make the pain go away.

PRT6 explained her experience with emotion suppression, relating them to being the oldest sibling. She shared,

> So, definitely in the past. And that's something I've been trying to work on, not suppressing my emotions as much. It's definitely still a work in progress, but that's how I've, yeah, that's how I've operated most of my life, suppressing my emotions. Being very together, being very together. I was used to being the one that, like, I'm, the older sister too. And so, you know I've got everything together, schoolwork is on point, social life, extracurriculars, so there weren't moments that I was allowed to break down because I was taking care of everything. I would feel like sometimes I'd take care of everybody. So, I didn't always feel like I had the luxury to show emotions. But that came, all came to like a boiling point I feel like at one point where it's just like, you know, I'm take I'm always taking care of everybody else; I'm always helping everybody else. Everybody thinks I'm fine, I have it together, so nobody checks on me. And I'm falling apart. And then in 2020 when COVID hit, I was having the worst time at my internship, the worst

> experience. It was my last two semesters. We went online to see clients; clients are dropping out because they don't like online. I don't know if I'm going to graduate on time. Everything just fell apart. Everything fell apart. I was having these horrible migraines. So, on top of the endometriosis and being in pain from cramps, I was also having these horrible, horrible migraines. And so, it got to a point where it was like I can't keep holding everything in. Like I have to express something. So, I'm learning my boundaries of what to express, when express, and knowing who to express it to. But with that also comes me speaking up more for myself like if I am at school or if I'm at work, if I need something or if I need a break, and not letting people work me to death. So, I'm a lot better now about expressing my feelings, but it's definitely been a big part of my history to suppress things and to keep them in.

PRT7 briefly explained her SBWS behavior. She stated, "Yeah, I do. I feel the need to suppress my emotions. I feel like I need to kind of hide parts of who I am while I'm at work just to be what is considered professional."

PRT8 related her emotion suppression to people's misunderstanding of the disease. She expressed,

> Yes, and that is also hard, because the disease affects your emotions really, because it's really like hormonal based a lot of, a lot of the symptoms are like really centered around your hormones. So, and you know your emotions are affected by your hormones. So, it's really, on a biological level, it's really hard to really do that, anyway. But, like I was saying with the last question, there are

> societal pressures of like having to put on this façade that this disease isn't really harming me because a lot of people really don't understand it, it's still a mystery. So, a lot of people don't, really don't know how to react when it comes to support in that way.

Resistance to Vulnerability. All of the participants answered the question related to their proneness to resisting vulnerability. Of the eight participants, seven participants indicated that they felt obligated to resist appearing vulnerable in various settings. One participant stated that it depended on the situation whether or not she felt vulnerable. This section reviews participants' perspectives regarding their proneness to resist vulnerability.

Regarding resistance of vulnerability, PRT1 had a brief response. She said, "Yeah, [I get] weak sometimes. Yeah, you know, because sometimes, emotionally, we get weak, we break down."

PRT2 discussed being vulnerable in certain situations. She commented,

> In certain situations, yeah. I told a lot of people I'm a very honest person. I'm always up front. I am very emotional and very sympathetic, so I kind of like keep it to the point. But I think certain topics, certain situations in my life. I kind of am very vulnerable, but other times I'm kind of like not vulnerable at all. So, I guess for me it just kind of depends on the situation.

PRT3 narrated her story regarding having limited support and her resistance to appearing vulnerable. She stated the following:

> Yeah, I would say yes to that too, yeah. Because I’ve done that also. Like, I don’t have friends or anything. So, all of my examples are really just like from my family and my partner. So again, like when I’m struggling with that kind of stuff, there’s been times where I try to be you know like vulnerable towards him. Sometimes it’s not like you need somebody to talk or give a solution or something. Sometimes I don’t know you just need somebody to hug you or something like that. But he’s not really physical like that I guess like as far as like hugging and stuff. So, there were times like in the past. I would go to help him, or something. You know how somebody would like tense up or like push you away and they’re like, you know I don’t like doing all of that, he calls it like “lovey dovey” stuff, like that or there’s times when I’ve been vulnerable like trying to open up about what I’m thinking and stuff and he’s like, you know, “You’re just always down and bringing the mood down,” so that has led me to, of course, like anybody you’ll be like okay, well, let me not be vulnerable because I don’t want anybody to shut me down because it hurts my feelings, so.

PRT4 explained her proneness to resisting vulnerability within the context of intersectionality. She shared,

> I think I do because I feel like if another person is mediocre that is White, it’s okay, she will learn. But I feel like, on the other side, for us (Black women) we’re fitting into spaces that were not created for us. So, no matter what’s happening like I know like everyone asked me why I cut my hair, and I was like, “Oh, yeah, it was time for a change,” not knowing that I just like, if I had to do another twist

> out in my hair, I don’t know what I would have done. So, it’s kind of hard to be transparent and vulnerable and say that I’m struggling, you know, I have this condition and my mood swings are unbearable and it’s hard to just tell the truth. Well, so what’s funny about it is one day one of my co-workers asked me why I was crying because I was in my cubicle, and I said, “Because I’m on my period,” and then one of the White girls came to me who had heard it and said “It’s like you don’t talk about stuff like that at work,” and I’ll say, “I really right now don’t have the space or the capacity for you to come into my cubicle with small chat or to tell me how today my hair is weird to you. I just can’t function.” So, yeah. So, I definitely think we are put in those [situations] to suppress telling the truth, or how we feel.

PRT5 explained that the complex nature of endometriosis was the foundation for her vulnerability resistance. She stated,

> Yes, only because I feel like, you know, sometimes like you feel you got to put on like a hardened like exterior because a lot of people don’t, I feel like a lot of people don’t understand what you’re really going through. They just think it’s just like normal heavy cycles, normal blood clots. Like that’s not normal. Like they just think, “Oh, yeah, you know, because you don’t have kids at 32, you’re just being safe” No, like I just feel like it’s other issues and people really just don’t grasp the concept to me. So, I feel like you have to like be so hard on the outside when on the inside you just want to cry or you just want to scream, or you just

> want to hide in the corner or something. So, I do feel like you just have to put on like a mask often times.

PRT6 discussed her vulnerability resistance within the context of the workplace and school environment. She explained,

> Yes, yeah going along with all the other themes. Yes, I do. I can be very closed off. And that's one thing that I think people they, the one thing that they comment on is that I can, or like at least supervisors, like I can be a little shut off. I can be a little closed off from people, and part of that is because I was taught, you know, you go to work, you do your work, you go home. Like we're not here to make friends. You do what you got to do. But I'm trying to find that balance of when, you know, when to be vulnerable, when to feel comfortable opening up. But I'm also very cautious, being the only Black woman in the room a lot of times, being the only Black person that I can't necessarily always be vulnerable, or be safe, because everybody does not have my best interest at heart. And so, some things that they may stay or do are not going to be seen as acceptable for me to say or do. So that's something I've been trying to work on is figuring out where and when I can be vulnerable. I think, being in the program I am now in the lab I am. My PI, she's a Black woman. All of my lab mates are women of color. Two of them are Black women. So, I think that's going to give me a space where I could do that. Yeah, I'm so excited. I think that's going to give me a space where I can do that without feeling like there's nowhere. So, a big part of what I've been trying to work on is building my community, building my network, things like

> that. Finding the people that I can be comfortable being vulnerable with. But it’s definitely always been a challenge for me to open up and be comfortable because when you feel like you’ve been burned so much, it’s hard to keep opening up.

PRT7 related her emotion suppression to privacy protection. She remarked, “Yeah, for the same reason. I just feel like, I, you know, those are things I need to keep to myself, and those aren’t things that I bring to work.”

PRT8 also mentioned having a limited support system as the rationale for her resisting vulnerability. She said,

> Yes, I do really just because a lot of times even when you do become vulnerable a lot of people don’t know how to support you. They don’t have the resources to support you. A lot of doctors aren’t really there to support you in being vulnerable. They’re just kind of there to treat you as a patient. So, the only like support system would be like friends and family, and a lot of times there is like such a thing as like, I forgot what it’s called, compassion fatigue, or something, and a lot of family and friends get tired of like having to continuously support you and not know what to do. So, yeah, it’s hard to be vulnerable in a space where you’re kind of ostracized by this disease because it’s a very unique disease, and the struggle is really unique to the person. But, in general, like the disease is really hard to understand in this huge struggle with it personally. So yeah, it’s hard to be vulnerable in a lot of areas.

Intense Motivation to Succeed. All of the participants answered the question related to their motivation to succeed. Seven participants stated that they felt obligated to succeed or achieve in various settings. In contrast, one participant explained that her depression caused her to no longer be concerned about succeeding. However, she stated that she used to be motivated to succeed before her depression. This section reviews participants’ narratives regarding their motivation to succeed or achieve.

Regarding the motivation to succeed, PRT1 offered a succinct explanation. She stated, “Yeah, I definitely have that.”

PRT2 shared a more in-depth rationale for her motivation to succeed and discussed being parentified as a child. She explained,

> I think with everything I’ve been through in my life, that’s where that motivation comes from. I know my counselor in high school I used to talk to her every day, she used to say to me, “You could write a book about your life, and somebody would buy that dang book, and there would be a million copies sold.” And I think with everything that’s happened like me taking care of my mother since the age of 7, me kind of having to become an adult at a young age and realizing what I’m doing, I think that strong motivation has caused me to be motivated how I am today.

PRT3 shared how depression reduced her desire to achieve. She stated the following:

> I used to (prior to becoming depressed and having children). I think, really, before I had kids I used to, because I would say like anything I do, I want to be the best at it even if it’s like just a small little cost in a job like I wanted to be the best at it. But I think now I would say maybe no. Because I don’t have time to make

> anything perfect, really. I kind of have accepted that. So, I was saying no like as in right now. It's like I kind of just let things go like you know if it's good, it's good. If not, you know.

PRT4 attributed her desire to achieve to the role models in her life. She stated,

> I'll say yes, for the most part because I feel like, how to say it, I think I've had good examples about, around me, about Black women exceeding and seeing people like Serena Williams, growing up with those models, like people who look like me (. …) So, I think I've seen that Black women can achieve if given the right circumstances, and go beyond race, no matter what. So, I would say yes.

Regarding the desire to achieve, PRT5 discussed being competitive. She offered the following narrative:

> Yes, so I am from like a small town in South Carolina. So, a lot of people like don't necessarily make it. A lot of people do, you know, start having children in like high school and stuff like that, and just get so caught up with the outside world, they don't have, I guess, goals or like, you know, maybe like more focused goals and stuff like that. So, I do just feel a need to always want to do more, achieve more. Try like, get like, you know, I'm always looking for what's next that I can do to make myself better, or to make me appear more successful than like somebody else or someone else type thing, if that makes sense.

PRT6 described being a first-generation college student and wanting a better life for herself and her children as being her motivation to achieve. She shared, Yes, I do. Again, being a first-generation college student, I feel there's always been a lot of pressure I feel for me to succeed, I will, and again it goes back to that feeling of I take care of people. So, there was always that point in my mind of like, okay, well, you know my parents they, they've done what they can with what they had, and they, you know, they took care of us. But still, there were times when there were things that we might want that we couldn't get. Or I look now, and their house is just, it really needs care and love and things to be taken care of. And seeing just their dynamic together, of how my mom she's more like, okay, well, I'm going to work, I'm going to take care of things and my dad is not really the same. He's older. He's retired, and so he's not as concerned about stuff. So, there's always been that motivation for me to be successful because I'm like, well, somebody has got to help my mom. Somebody's got to, you know, help her to get the things that she needs or things that she wants. But then also there's that part of me that's like I got to succeed also for me because I want my kids, when I have kids, to have more opportunities to be, to not worry about the things that I worried about. Like I've worked since I was 15 and I'm tired. And it's not going to slow down anytime soon. And so, I want them to be able to, you know, live a life where there're things they don't have to think of, there're things that they don't have to be aware of because they're taken care of. And so that's what's really important to me. I want to get to a point where I'm living a life where I'm free, and I don't have to worry about things like my debt or things that would stress me out. I don't want to have to worry about like, "Am I going to be able to

> pay for this? Am I going to be able to get this?" I want that life for me, and I want that life for my children when I have them.

When questioned about the desire to achieve, PRT7 emphatically responded, "Yes, 100%. I've always been, I've always very much been an overachiever, and feel like I need to do everything I can to be successful. So yeah, I do feel the need to overachieve and to be successful."

PRT8 recounted her motivation to achieve within the context of intersectionality. She explained,

> Yes, but I think that's just innate for me because I'm highly self-critical. But, other than that, I think the struggle with endo specifically, it makes you feel like you're already on a setback. So, it kind of feels like you're always playing catchup, or like always trying to like race to the finish line. You're always two, three steps behind everyone else. So, I think, yeah, there is a pressing sense of having to achieve success. I mean, yeah, being Black and having endo and being young. And yeah, a lot of different pressures from different angles to be great while also not really getting the same, even level playing field as other people. So, it's already like you're playing catchup. So, there are so many different, so many different things. So many different things holding me specifically back.

Obligation to Help Others. All participants answered questions related to their feeling obligated to help others. Seven of the eight participants indicated that they felt compelled to help others. Only one participant, PRT7, expressed that she did not feel obligated to help others. This section recounts participants’ narratives regarding their likelihood to help others.

When questioned about the desire to help others, PRT1 shared that her profession involved helping others. She explained,

> That’s what I do for a living, even when you’re vulnerable or feeling emotional, you know, emotional distress. Yeah, sometimes, often yes, to answer that question. But sometimes I feel like the episode can go differently just because, like, one day, I could be at work, or, like I said, the pain can hit so bad. I want to cry like I’ll just go in the bathroom and get it done and get it over with, and I’ll come back out I’ll be fine but pop a Tylenol or something. But there’s actually been times where I’ve actually broke down, broke down like crying, sobbing; felt like something was wrong with me. Like, “Why me?” and all this other stuff. So yeah, sometimes it can be worse than others. I will say that, and it makes me question sometimes about myself.

PRT2 explained that she had spent her entire life caring for others. She stated,

> Yes, I have this thing of kind of like putting others before me, and a lot of people have told me that I shouldn’t do that, but I do it all the time. I kind of feel that a part of me feels that I was put here to kind of help people in a way. That’s kind of why I’m going into a health field. I kind of like put my needs last and I’m starting to not want to do that because I know it’s not good, but it’s kind of like I’ve been doing it my whole life, taking care of people. It’s kind of like, why stop now?

PRT3 reported feeling responsible for others and expressed her propensity to help others. She stated the following:

> Yeah, I would say, yeah, again, I do. And I find I know that about myself. I think I'm overly like "Let me make sure everybody else is okay. Let me make sure I do this for everybody else." in our whole household. I'll make sure everybody else has eaten, in the bed, they're showered, and gone to sleep like everything before myself. And I've really been trying to look into why lately. I think it's because anytime I have felt bad or something, even with my kids or my partner, I'm like, I don't ever want them to feel like that, so like, let me jump in and try to solve everything and help everything, help them with everything. But I think that's why I feel like that.

Regarding helping others, PRT4 referred to her cultural training. She concisely stated, "I unfortunately do because it's embedded in my training, right?" I've been raised as a nurturer, so even if I don't want to, I end up feeling bad [if I do not]."

PRT5 justified her inclination to help others because of her kind nature. She shared,

> Yes, only because I feel like I'm genuinely a nice person. So, I really do try to, you know, advocate for others to try to like be there, you know, mentally, emotionally, even though sometimes, I'm physically not there. So, I do feel like, yeah.

PRT6 recounted her mindset changes related to helping others. She explained,

> Yes, not as much as it used to be. It used to be, like I said, I had that caretaker type of mentality. I've definitely grown out of that, finally. So, I don't feel the need to take care of others as much as I used to. But that definitely was, I'd say, my personality growing up. I was always taking care of people, and I think I was always just put in the position to take care of people to the point where it got to, well, this is how I get love, or this is how I get what I need. I have to take care of other people. If I don't, they'll leave. And so having to unlearn that has brought me to a point where now I don't feel the need to have to take care of people, or even if I feel that urge of like, oh, I think I'm getting into that caretaking, I'm able to step back and be like, "Oh, no! They got it." Like, what would you do if I was not here? Like, you can, you'll figure it out. But, if people need support, if people need help, I'm still there. But I'm not offering to do any and everything because, again, being the oldest child, I like, at home, I go back home, and I'm literally everything. I'm the cook; I'm the hairdresser; I'm the copywriter; I'm tech support. I become any and everything if I allow them to use me to be any and everything.

PRT8 shared that she feels that the COVID-19 pandemic caused people to have to rely on each other. She expressed her experience as follows:

> So, a lot of the time, I feel obligated to step up for my community because we don't have many people rooting for us in any area of life. But in general, specifically in the hospital, and even more specifically, or in the medical field in the hospital and just in general health care, but more specifically like care with

> endometriosis because we are kind of denied that. And especially me being young and Black, it's even harder for them to see me as someone who is struggling with such a destructive disease. So yeah, it does feel like a lot of the weight falls on me and other Black women to really educate us, like, educate ourselves and educate each other because a lot of the time, these doctors will deny us the right to help, or education or resources or accessibility to these resources. So yeah, I'd say that it's a huge responsibility. Not only is the disease itself a responsibility, but you feel a responsibility and a calling to help the people like you because no one else will; at least, it feels that way.

Intersectional Nature of Being a Black Woman in the United States in Health Care and Other Settings

Participants commented on how it felt to be a Black woman in the United States in various settings, including health care settings, the workplace, academic settings, and at home. Comments related to this theme were frequently expressed relative to the SBWS characteristics. The participant narratives described below were mainly in response to the question regarding whether the participants felt that being Black women impacted the quality of their care. The women discussed discrimination in the workplace, experiences with poor support systems in various settings, disparities in treatment by their doctors, and inadequate treatment while under their doctor's care. Several women reported that they had to change to Black or female providers to get adequate or better care. Also, as mentioned above, four of the eight women explained that their doctors recommended a hysterectomy to solve their endometriosis pain and other symptomology. This result aligns with findings indicating that Black women are disproportionately more likely to have a hysterectomy for benign conditions such as endometriosis (see As-Sanie et al., 2019; Jacoby et al., 2010). Participants offered multiple stories related to their experiences with intersectionality throughout the interviews. Impactful statements related to this topic are included in this section.

PRT1 discussed intersectionality and her experiences with discrimination. She reported as follows:

> Yes and no. One, let alone being Black, too, being a woman, a Black woman. I will say that, when it comes to my care, I actually do take that into consideration. I am one of those. I’m a very picky person with my care, like if I have a doctor’s appointment and I walk in, and she’s telling me I got a student here [that is going to treat you]; that’s going to be no. I’ll tell her I don’t want a student. I’m not, so get somebody else. Like, I’m very picky. So, with that being said, I will not see a male doctor. My experience with male doctors [is that] they feel like they’re too high up like I’m down here. I need help, you know. They just do too much. So, I’m one of those people, I prefer a female doctor. I do lately. Within the last two years I have been reaching out to a lot of Black-owned clinics, businesses seeing what they’re about just because they’re a Black woman, just like me and, you know, they know about stuff that I’m going through. And some, I’m not trying to be funny, I’m not trying to pull the race card, but some of these Caucasian doctors out here, they just don’t care. That’s how I feel. I’ve had a lot of them ignore me when I tell my symptoms. I’m not understanding that; you’re supposed to be a

> doctor. You're supposed to help me rather if I'm yellow, orange, or blue. Like they'll go in another room, and it'd be a totally different scene with another patient and find out later on maybe it's because, you know, they're a Caucasian or whatever. I've seen the race card being played a lot in medical care, so lately, I'm trying to stick with the more African-American side, just to be honest.

PRT2 told her experience with being Black and intersectionality. She shared,

> I always used to tell myself that if I wasn't Black, it would be easier. My family told me a story that when I was younger, I used to hate being Black, and now I kind of think about it, I'm like, did I really say that out loud to a lot of people. And I think now with the stigma, or the kind of like norm that people have towards Black people, I think now I'm proud to be a Black woman. You know, there's a lot of things we go through, not only by our gender, but also by our race, and that mix together can cause a lot of things.

PRT3 changed her care to a doula and a midwife, who she felt listened to her better and provided helpful treatment recommendations. She stated that another benefit of switching to a doula and midwife was her significant other being included in her care as her partner and children's father. She richly described her experience as follows:

> Oh, yes, it (being Black) definitely has (impacted the quality of care). Even like you just go to the emergency room, sometimes it seems like they're just quick to, you know, diagnose you with something, or they give you medications. And then, especially when it comes to childbirth and like just being pregnant and stuff, I had one obstetrician I was going to, and it was like she would be like okay, as soon as

> you get to 37 weeks, we're inducing you. And then my boyfriend was like, "You know why?" Like, you know, I didn't have any health problems or anything. Even with the endometriosis, it wasn't a high-risk pregnancy or anything. So, my boyfriend was asking why, and she was like, "I have a vacation scheduled that week," and we immediately just switched to the midwives and stuff, and all of them are African American. And when I was telling them that (the situation with the doctor wanting to induce labor), they were like, you know, that's when they really let me know about the mortality rate for African American women when they give birth and all that kind of stuff. And they were like, the fact that she said that she's choosing to induce you at 37 weeks because she has a vacation. It made me feel like okay, you know, I'm not important to them. It's just like, you know [I am] just a number like I need to go ahead and deliver this baby so she can go [on vacation].

PRT4 expressed her experience with intersectionality and discrimination within the workplace. She also described how Black women are trained to be wives and images of strength. She explained as follows:

> And then things like, it's usually like working for a White company, it's more like I don't want them not to be able to hire more Black women, so I can't be the one to be like taking off more. I have to work extra hard, and then, so it's just a lot. There's a lot of, even the Black men, the way they treat the Black women like the way Black women are treated in society. Like even Breonna Taylor, like the way they like if anything happens, they find a way to want to drag us down. So, I think

> as Black women, all we've been taught is to be wives. Like one day, when I get married, you have to do all these things, and I feel like that's all we know is to be taught to be an image [of a strong woman]. Then, later on, maybe you hear that oh, man, like one of my aunts, I didn't even know she had endometriosis, you know. Because she never was given the opportunity just to be. She had all these millions of things to do.

PRT4 discussed having her pain invalidated as a Black woman. She shared,

> I definitely think 110%. I think because if I told you I'm in pain, like I don't think this is normal, you shouldn't shove birth control down my throat. You should ask, hey, maybe we need to do a scan, an extra scan, or maybe we do other things. So yeah, I definitely think that women, especially Black women, are taken less seriously about their pain. Okay, but I also don't know in medical school if they train specifically for other races. Or is the pain threshold equated to what they know?

Moreover, PRT4 recalled that she had received better care while under the treatment of her current doctor, who was Black woman. She also suggested that her poor medical treatment might have been her fault. PRT4 shared her sentiments as follows:

> But I think, and maybe it's my fault, too, because traditionally, I didn't care like what color the doctor was until one of my coworkers at the time was like, "No, you need to go see a black doctor." So, I think at the time I started working when I was 22, and one of my co-workers saw that I was like struggling the whole time. It's like, "No you need to go to this doctor, she's Black, and she's known to like

> really care for your needs." And after that, we did the test and all that stuff, and that's what happened.

Lastly, PRT4 shared this additional experience with intersectionality:

> And then I am also very passionate about human rights. So, it was also race, and on top of that, I work for a Republican company. So, it was just, for me it was just a lot. Especially when they started now trying to talk about race at work. Everything was just like too much. I wouldn't have been able to survive that year if I hadn't started seeing a therapist. So, for me it was just more like they were trying to have the conversation that "We're not racist." And they'll be like the Black people on the Zoom call should talk. Like stuff like that.

PRT5 explained her perspective related to being invalidated by her doctors. She shared,

> I've dealt with issues for years, and I feel like I've been having to be like silent. So, a lot of times you take that silence, and you just kind of like go along with it a little bit. And so, like it gets to a point where you can't do it anymore. And so, I feel like people don't understand because they feel like "Oh, well, are you really in pain? Is it really pain? Or is it just like normal? Are you over-exaggerating?" I feel like, you know, I often get that, you know. "Is it really like, you know, that hard?" So, I feel like I haven't been getting adequate care. I feel like they have, like I said, they've been putting band-aids on stuff that like needs to be addressed. I just feel like, yeah, it's not right. Like I feel like I've never gotten anybody

> that’s gotten down to like the root of the issue. Yeah, telling me to lose weight or telling me to walk a mile a day. That don’t help.

PRT6 reported similar sentiments to PRT5 regarding her doctor invalidating her concerns. She stated,

> Yes, I don’t believe I’m always believed when I say things. My primary care that, you know, I’ve had since I was, I think, maybe a teenager. My mom and I, we’ve always had the same doctor, so wherever she went, I went. So, this last one, she is a woman of color, but she doesn’t seem to take me all that seriously. I feel when I tell her things, or if I bring up a concern, or if something is bothering me, I feel like it’s often brushed off, of not being like really all that serious.

PRT8 explained her experience with intersectionality in health care settings. She shared,

> Yes, there’s been plenty of times where I’ve been in the hospital where I’ve been in emergency situations or urgent situations, even outside of endometriosis, and I’ve been ignored, I’ve been laughed at, I’ve been mocked, I’ve been denied care, I’ve been disrespected, all while like in this emergency situation. So, none of this is helpful. But yeah, I think just, in general, the health care system fails women. But it’s failed specifically Black women in general because I think our pain is just never heard, it’s never believed, it’s never really treated with care and especially the care that other women get. I think a lot of like the struggle is that our initial obstacle is like even getting a doctor to believe that you’re in pain or believe that your pain is real or believe that you know it’s not just something small, or you

> know, so it’s hard to really even be believed to even get to the health care part, so, yeah.

Summary

Chapter 4 captured the analytical findings of the interview data and information, relevant themes, and aligned categories that resulted from the analysis, research setting, participant demographics, data collection and analytical processes, and evidence of the trustworthiness of the results. After conducting interviews with eight participants, I edited the audio-recorded transcriptions, reviewed the final transcriptions for accuracy, and sent copies to the participants. Then, I uploaded the data into NVivo software for coding and organization. I refined the organized and coded data to produce 14 categories and four themes. The four identified themes include health, life with endometriosis, The U.S. health care system, and the nature of being a Black Woman in the United States. The topics discussed within these themes include physical and mental health, symptom management, delayed diagnosis, perceived level of care before and during the COVID-19 pandemic, the nature of endometriosis, the impact of endometriosis on the participants, the significance of a support system, insurance coverage, resources and research, the overall quality of provider care, the SBWS, and the intersectional nature of being a Black woman in health care and other settings in the United States. Table 2 breaks out the structure of the categories and themes that emerged from the data analysis. Table 3 through Table 6 demonstrate the frequency the participants endorsed or discussed the subthemes or categories. The identified themes aligned with the three research questions in the study as follows:

RQ1: What are the lived experiences of Black women with endometriosis during the COVID-19 pandemic?

Regarding this research question, the analysis found the following:

1. Seven participants had chronic pain associated with endometriosis.
2. Seven participants experienced mental distress associated with their endometriosis symptomology before and during the COVID-19 pandemic.
3. All participants experienced a host of symptoms and used various forms of treatments and symptom management techniques and practices.
4. Six participants had a delay in their diagnosis.
5. All participants reported having at least four characteristics related to the SBWS.
6. Seven participants’ narratives included racial disparities in treatment within the health care system and other settings.

Notably, none of the women mentioned fear related to catching COVID-19. However, one participant was hospitalized for it. These key findings revealed that Black women experienced the same symptoms, engaged the same pain and symptom management practices, had the same concerns (i.e., infertility, delayed diagnosis, and ineffective pain treatment), experienced mental anguish, and had the same feelings about their providers than non-Black women did. On the other hand, the Black women participants indicated that they engaged in negative “superwoman” and “caregiver” behaviors related to the SBWS that proved harmful to them during the COVID-19 pandemic, which isolated and silenced them within an already restrictive environment.

The participants also talked about experiencing racial disparities in the health care system, i.e., being treated unjustly by their doctors and being dismissed, mocked, laughed at, and discredited regarding their feelings about their bodies.

Moreover, the analytical findings indicated that most participants felt they did not receive adequate care before the COVID-19 pandemic. Most importantly, when addressing the third research question about their perceived level of care during the COVID-19 pandemic, most participants felt that they received better care during the pandemic than they did before the pandemic. These findings require more exploration and have implications related to a German study, reviewed in Chapter 2, that found social distancing (due to COVID-19 restrictions) and dysmenorrhea to be negatively related (Schwab, 2021). This finding also warrants further investigation because the results indicated that most participants were dissatisfied with the pandemic restrictions because of the unavailability of in-person appointments and long hospital waits. Two participants felt they received inadequate care during the COVID-19 pandemic due to the challenges of successfully making appointments with providers.

In comparison, five participants stated that they received better care during the COVID-19 pandemic. However, most participants remarked about challenges with making provider appointments due to the COVID-19 restrictions, regardless of their perceptions of the level of care. One participant felt there was no difference in provider conditions other than the inaccessibility of in-person appointments. She said the health care system “needs a lot of work, regardless.”

RQ2: How do Black women manage their endometriosis-related symptoms during the COVID-19 pandemic?

All eight participants said they engaged in various symptom management practices, techniques, or treatments. Notably, when they discussed their symptom management, they mentioned how they managed their physical pain, symptoms, and mental distress. The women used prescribed treatments, such as pain medications, birth control pills, birth control patches, psychotherapeutic treatment, and hormone therapy. Also, most participants found that pain medications, like Midol, Tylenol, and Pamprin, were ineffective, mentioning that they often “overdosed” or took excessive pain pills and still experienced intense pain. Participants also used treatments such as pelvic floor therapy. Several participants indicated that it was during the COVID-19 pandemic that they began engaging in self-care and other self-management behaviors to help mitigate the adverse physical and mental health effects of endometriosis symptomology. The participants stated that they practiced lifestyle changes. They also mentioned using home remedies such as meditating, taking hot baths applying heating pads, using essential oils, lying on the floor, doing stomach massages, using more natural products such as natural pads, changing their diets, and establishing an exercise routine. At least half of the participants explained that they used psychotherapy as a form of treatment for their symptom management. However, most of them were not knowledgeable about the impact that endometriosis, specifically CPP, could have had on their mental wellbeing. This result indicates a need for doctors and Black women to have access to education regarding endometriosis symptomology and its potentially harmful effect on Black women's mental health.

These findings aligned with existing literature regarding symptom management for women with endometriosis during the COVID-19 pandemic. Leonardi et al. (2020) found that women employed problem-focused and emotion-focused strategies during the COVID-19 pandemic due to negative feelings and restrictions related to the pandemic environment. The strategies that the women used catered to the physical and mental health needs that these women faced before and during the pandemic, which aligned with findings by Leonardi et al. Therefore, the research findings revealed that the Black women participants engaged in the same pain management techniques as non-Black women. However, understanding the connection between physical pain and mental anguish seemingly eluded the participants. Also, as aforementioned, the participants engaged in harmful SBWS behaviors, often suppressing their feelings and pain. As expressed above, the women reported feelings and behaviors related to the SBWS, which aligned with existing research as reviewed in Chapter 2 of this study. The participants all reported behaviors reflective of internalization of the SBWS roles, often mentioning having to appear strong instead of being vulnerable or weak to protect themselves (or the Black race) from harmful stereotypical judgement. The women also discussed not wanting to burden their family and others. These results aligned with existing literature by Abrams et al. (2019), Carter and Rossi (2019), Green (2019), Liao et al. (2020), Stanton et al. (2017), Watson-Singleton, 2017 and others who revealed the detrimental psychological and physical effects that the SBWS has on the Black woman.

RQ3: How do Black women perceive their mental health and medical care for endometriosis-related symptoms during the COVID-19 pandemic?

Research is limited to the nature of this questions. Therefore, I did not have much literature to reference when analyzing the responses to this question. However, the results aligned with research that determined a relationship between quality of life, psychosocial stress, anxiety, depression, and endometriosis among African women (Roomaney et al., 2020); this literature is reviewed in Chapter 2 above. Most Black women in this study also had moderate to severe depression and echoed concerns regarding sexual relationships, health care and the medical profession, and physical functioning. One interesting observation I noted was that several participants did not connect their physical pain and mental distress during the interviews, even though most experienced both. So not only were they suppressing their pain and emotions sometimes, but they were not aware of the relationship between them.

Moreover, all eight participants responded to questions about their perceived level of care during the pandemic and reported that their perceived level of care heightened during the COVID-19 pandemic. As discussed above, five participants felt they received better or more adequate care during the COVID-19 pandemic than before the pandemic. Only three participants expressed that they felt they received the same level of care or lower during the COVID-19 pandemic. Of the five participants who indicated that their level of care was better during the COVID-19 pandemic, two had conditions requiring hospitalization or specialized attention during the COVID-19 pandemic. One of the two participants attributed her perception to being pregnant and changing her care to a doula and midwife. The other participant mentioned that she contracted COVID-19 while having heart issues, diabetes, and thoracic endometriosis impacting her lungs, which caused doctors to pay closer attention to her needs, providing her with alternative medications and treatments. Also, as mentioned previously, most participants engaged in self-care and other self-management practices due to confinement to their homes during the pandemic, limited accessibility to in-person and virtual provider appointments, and long emergency room wait times.

Regarding mental health, all eight participants mentioned that their providers did not inquire about their mental distress in light of their physical endometriosis symptoms. The participants seeking psychotherapeutic support or medicinal treatment for their mental distress had to be proactive and mention their mental states to their doctors or practitioners. One participant mentioned that she could not manage her endometriosis pain and other changes related to COVID-19 restrictions and concerns, so she decided to start seeing a therapist independently.

Chapter 5 will include a summary of the study, conclusions associated with the study, and recommendations. Specifically, the next chapter will present an interpretation of the study findings, identify the study’s limitations, present the recommendations and implications, and end with a conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

This qualitative IPA study was designed to explore the mental health of Black women with endometriosis-related symptoms during the COVID-19 pandemic. I interviewed eight Black female participants who stated that they were residents of the United States, between the ages of 18 and 40, and diagnosed with endometriosis requiring care during the COVID-19 pandemic. I aimed to understand Black women's perceptions of how COVID-19 restrictions might have impacted their mental health related to their endometriosis symptoms. As a result of the analysis, four themes and 11 subthemes were identified as follows:

- health (physical health, mental health, symptom management, delayed diagnosis, perceived level of care before the COVID-19 pandemic, and perceived level of care after the COVID-19 pandemic)
- life with endometriosis (nature of endometriosis, impact of endometriosis, and support systems)
- U.S. health care system (insurance coverage, resources and research, and overall quality of provider care)
- nature of being a Black woman in the United States (SBWS and intersectional nature of being a Black woman in health care and other settings)

These themes and subthemes revealed the significant factors related to understanding how endometriosis symptomology might have impacted Black women and their level of care during and before the COVID-19 pandemic. This chapter includes a discussion of these themes, how they are parallel to findings in existing literature, and how they align with the research questions in the current study. I also provide an interpretation of the findings, limitations of the study, recommendations as a result of the study, implications for positive social change, and a conclusion.

Interpretation of Findings

Findings aligned with existing literature as reviewed in Chapter 2. The parallels between existing literature and findings from data analysis in this study are relevant to the SBWS, the biopsychosocial treatment model, and other research related to how endometriosis impacts women. The interpretation of the findings is organized by the identified themes.

Health

This theme was the first identified in the study. Health included categories such as participants' physical health, mental health, symptom management, delayed diagnosis, and perceptions of their level of care before and during the COVID-19 pandemic. The most prevalent issue that surfaced during the interviews was chronic pain related to endometriosis. The word "pain" was mentioned over 160 times during the interviews and was the most common physical symptom referenced among all but one participant. Participants described their pain as being debilitating and as "extremely painful, "excruciating," and "chronic."

Other symptoms that the participants mentioned included heavy bleeding and clotting, mood changes or mood swings, development of ovarian cysts, dysmenorrhea, dyspareunia, and irregular periods. Also, most participants mentioned that pain medications were ineffective. Three participants said they often took excessive doses to attempt to treat their pain but the pain persisted. Many participants referred to their misery as lasting longer than their menstrual cycle, often having pain that occurs before and after their periods. Several participants expressed their concerns about taking birth control pills to mitigate the pain, cysts, and other symptoms, mentioning that the weight gain and mood changes associated with birth control were undesirable. Mental distress was also a common issue that the participants mentioned, mainly citing anxiety, depression, and mood swings as the source of their mental anguish.

The women’s reporting aligned with existing literature regarding delayed diagnosis and misdiagnosis related to misinterpreting menstrual cycle complications (see Berterö et al., 2019). Also, the women described their physical and mental symptoms that indicated the same symptoms as described in research by Agarwal et al. (2019), As-Sanie et al. (2019), Fauconnier et al. (2013), and Pereira et al. (2021). Regarding health, participants had some of the same mental health issues, physiological symptoms, and experiences before and during the COVID-19 pandemic as non-Black women or women who lived in other countries (see Arena et al., 2021; As-Sanie et al., 2019; Demetriou et al., 2021; Evans et al., 2021; Ramos-Echevarria et al., 2021; Rosielle et al., 2021; Rowe and Quinlivan, 2020; Schwab et al., 2021).

The notable difference that warrants further research is that current participants felt they received adequate or improved care during the COVID-19 pandemic despite confronting limited availability of provider appointments, extended hospital waits, and ineffective treatments (mainly inadequate pain medications). Treatments and remedies for symptom management included the following:

- having appointments with providers
- taking birth control pills and using birth control patches
- making changes to diets
- starting exercise routines
- using pads made of natural materials
- taking pain relievers, doing pelvic floor therapy
- receiving hormone therapy
- massaging the abdomen area
- taking hot baths and using essential oils
- applying heating pads to the affected areas

These findings indicated that the Black women in America employed the same self-care and self-management activities before and during the COVID-19 pandemic as other women (see Arena et al., 2021; As-Sanie et al., 2019; Demetriou et al., 2021; Evans et al., 2021; Ramos-Echevarria et al., 2021; Rosielle et al., 2021; Rowe and Quinlivan, 2020; Schwab et al., 2021). Also, half of the participants were encouraged to have a hysterectomy to resolve their pain; they all rejected this recommendation. These findings also confirmed existing literature that Black women are offered hysterectomies more often than non-Black women (see Alexander et al., 2019; As-Sanie et al., 2019; Jacoby et al., 2010).

Regarding a delayed diagnosis associated with endometriosis, six of the eight participants reported experiencing a delay in their diagnosis. The most prolonged diagnostic delay was a participant whose menstrual cycle started when she was 9 years old; however, she was not formally diagnosed until she was in her 20s. This recurrence of a delayed diagnosis in women with endometriosis was a theme in current literature. This topic and the women's accounting of their delayed diagnosis experience aligned with existing research that referred to delayed diagnosis as a theme reported by non-Black women with endometriosis (see Berterö et al., 2019; Bull & Hearn, 2021; Facchin et al., 2018; Morardi et al., 2014; Rea et al., 2020). This theme appears to be shared among many women diagnosed with endometriosis, regardless of their demographic characteristics.

Participant perceptions regarding their level of care before and during the COVID-19 pandemic were central to this study. However, in seeking to gain a deeper understanding of these topics, I noticed other matters. I found that most participants perceived their level of care as more adequate during the COVID-19 pandemic than before the COVID-19 pandemic. However, most participants also agreed that the limited availability of face-to-face or remote appointments and long emergency room waits associated with COVID-19 restrictions were inconvenient and negatively impacted the level of care they received at the height of the pandemic. These finding aligned with the results by Ramos-Echevarria et al. (2021). The limited access to providers due to pandemic restrictions motivated the participants to adopt more self-care and self-management practices and techniques, seek psychotherapy, or seek alternate types of providers (e.g., doulas or midwives).

These findings implied that the participants felt better trying alternative forms of treatment, using doulas and midwives, and self-managing their symptoms instead of relying on their providers’ care to treat them. These findings aligned with existing literature by Demetriou et al. (2021). However, this topic needs further exploration. Additional research might promote a better understanding of why most current participants felt their level of care improved despite their acknowledgement of pandemic restrictions and reliance on ineffective pain medications and pain self-management.

The findings from the current study related to the participants’ perceptions of their level of mental and physical health care during the COVID-19 pandemic were new and addressed a gap in the literature. However, the findings related to how the participants felt regarding the level of care they received prior to the COVID-19 pandemic were consistent with existing literature. Six of the eight current participants asserted that they did not think they received adequate medical care for endometriosis before the pandemic. These participants referred to their experiences of not being listened to or validated by their providers and their providers recommending treatments that they described as harmful, ineffective, or not understood. As assessed in the literature review, Pettersson and Berterö (2020) and Grundstrom et al. (2018) found similar results in their studies. This finding represents a universal theme among women of various ethnicities, races, ages, countries of origin, and other demographic qualities that some women with endometriosis feel that doctors do not validate their concerns. Women also feel they must question their doctors’ competence and capacity for empathy and understanding.

Life With Endometriosis

This theme included categories such as endometriosis’s nature, the impact of endometriosis on participants’ lives, and the significance of having a support system.

When I asked the participants to provide one word that comes to mind describing life with endometriosis, they used the following terms: misunderstood, hell, eve, difficult, handicapped, powerful, painful, and normal. These words describe the complex nature of endometriosis as articulated by eight women, with responses ranging from no pain and irregular periods to silent endometriosis to extreme pain and many symptoms connected to other types of endometrioses.

When discussing the impact that endometriosis has on their lives, the women commented on how being a Black woman and having endometriosis has impacted their lives. The women explained that endometriosis had impacted their daily activities and overall quality of life, fertility and childbearing, work life, student experiences, sex life, income and productivity, and other areas of their lives. Support was another topic that surfaced while interviewing the women. They described the complexity of their support systems and how they sometimes lacked support from their providers, family, coworkers, friends, and significant others because of endometriosis's complicated and misunderstood nature. This finding aligns with existing literature based on research that found that the SBWS is associated with the perception of reduced emotional support and increased mental distress (Watson-Singleton, 2017). The topic of emotional support warrants further investigation because most of the participants in this study indicated that support was essential when coping with endometriosis symptoms, and all of them expressed that one word was insufficient to summarize the complex experience of living with such a misunderstood, painful, and incurable disease.

Also warranting further exploration is the degree to which Black women identified the SBWS and their endometriosis-related chronic pain with their mental illnesses. Some participants appeared unaware of the deleterious influence that the SBWS, coupled with chronic endometriosis pain and other symptoms, can have on their overall quality of life and mental and physical health. Although I explored how Black women fared with having endometriosis symptoms during the COVID-19 pandemic in the United States, the pandemic appeared not to have much of an impact on these women's mental health; however, their endometriosis symptoms did. One participant narrated how the working conditions during COVID-19 restrictions and SBWS behavior, coupled with her endometriosis pain, exacerbated her depression and mental distress to the point of needing to obtain psychotherapeutic care. Otherwise, COVID-19 conditions along with endometriosis symptoms were not reported to have directly impacted the women's mental health.

U. S. Health Care System

This theme included categories such as insurance coverage, resources and research, and the overall quality of provider care. Of eight participants, six mentioned that they believe the quality of the U.S. health care system needs improving. Only two participants indicated that they were satisfied with their health care. Three participants commented on the lack of available resources, research, and funding for endometriosis to advance its cause, raise awareness, and better understand the disease's nature and how it affects women. Participants discussed how doctors seem not to know much about the disease or effective treatments for the disease. Notably, all participants expressed that their providers did not address the impact that endometriosis pain can have on women’s mental health. Some participants mentioned that their doctors seemed to lack general education about endometriosis and treatment. Several participants mentioned that their providers lacked diversity education or cultural sensitivity regarding Black women and their health. Also, one participant was unsure why she was taking birth control pills for endometriosis because her doctor never provided an explanation. Also, several participants communicated having insufficient insurance coverage, lapses, and other insurance issues preventing them from receiving the mental and medical care they needed. One participant expressed that she felt like the policymakers in the health care system have no idea what Black women go through in a day and that she should have created an extra budget to support her health care needs.

These findings aligned with the findings by Walton et al. (2021) who found that Black women were more apt to die after contracting COVID-19 due to the lack of access to affordable health care. Walton (2021) also pointed out that these women carry a mental and financial burden related to the COVID-19 pandemic and systemic racism that overlaps other oppressive systems. Also, the participants’ reporting regarding research voids for endometriosis advancement aligned with the findings of existing research including non-Black women (As-Sanie, 2019).

Nature of Being a Black Woman in the United States

This theme included categories such as the participants’ perceptions regarding their characteristics related to the SBWS and the intersectional nature of being a Black woman in various settings in the United States. All eight participants answered questions regarding the degree to which they possess characteristics associated with the SBWS. The findings indicated that all participants felt obligated to display an image of strength, even when experiencing endometriosis symptoms such as pain or heavy bleeding. Seven participants felt obligated to resist feeling vulnerable, had an intense motivation to succeed, and had an obligation to help others. The findings also revealed that six participants felt obligated to suppress their emotions. In contrast, two participants once felt obligated to suppress their emotions but are currently trying to improve this behavior. The participants attributed their behaviors to multiple factors, including modeling their mother’s behavior, not wanting to be seen as an angry or inferior Black woman, being the only Black woman or Black person in the room, being misunderstood or not wanting to burden their family members, racial discrimination or lack of cultural sensitivity, and other factors. These findings aligned with existing research literature related to the SBWS. These findings are intricately connected with another category in this theme, the intersectional nature of being a Black woman in the United States in the health care system and other settings. This topic also relates to the SBWS or themes in Black feminist thought theory, a “critical social theory” (Collins, 1990), which speaks to Black women’s oppression in the United States, namely racism and sexism.

Moreover, these women face prejudicial and stereotypical images that they have internalized, such as the “mammy,” while confronting gendered racism, which attributes to their desire to suppress their pain and vulnerability to appear strong. Some participants revealed facing systemic shortcomings regarding their inability to afford adequate health care. Two participants talked about the impact of being young with a chronic illness like endometriosis while also being Black and a woman. Several participants reported that they had to change to Black providers, a doula, or a midwife to receive sufficient care. Participants also talked through the following topics:

- being treated differently for being a Black woman on work-related Zoom calls
- being treated differently by doctors due to being a Black woman
- having their symptoms invalidated
- being treated with a lack of empathy
- being disrespected and disregarded in emergencies

For example, as mentioned above, PRT4 discussed that Black women could not get away with being mediocre at work like White women and mentioned how Black women are treated in society, even by Black men. She mentioned the Breonna Taylor incident and stated that society tries to bring Black women down if anything happens. The women's reporting on how it feels to be a Black woman in the United States, intersectionality, and the SBWS aligns with current research were reviewed in Chapter 2 of this study. In Chapter 2, I reviewed research literature regarding oppression associated with being a Black woman in the United States (see Abrams et al., 2019; Carter & Rossi, 2019; Green, 2019; Liao et al., 2020; Stanton et al., 2017; Watson-Singleton, 2017).

Limitations of the Study

One limitation of the study was the sample size of only eight participants. I originally planned to interview 12 women. However, as discussed in Chapter 3, four of the 12 participants only met some of the requirements. Therefore, the participant sample size was eight participants and smaller than initially intended, impacting the variability among participants. This reduction in the sample size could potentially limit the study’s transferability. Another limitation was that all but one of the participants were single, which also impacted the variability of the participant sample. Also, despite the participants living in various cities in the United States, no participants were located on the West Coast. Also, despite the participants living in various cities in the United States, there were no participants located on the West Coast. The participants were primarily located in the southern, eastern, and midwestern regions of the United States. This factor also contributed to the limitations related to the variation in the participant sample. Another possible limitation related to the sensitive nature of this study’s topic which may have caused participants to avoid discussing some issues. Lastly, a potential limitation was related to the nature of the interview. The researcher must have confidence in the integrity and completeness of the interviewees’ reporting while acknowledging the possibility of limited disclosure of some information that might have otherwise been germane to the study.

Recommendations

The findings in this study indicate that the U.S. health care system needs to incorporate more funding dedicated to research and resources for Black women with endometriosis. This funding should also be dedicated to raising providers’ and the general public’s awareness regarding the complex and intrusive nature of endometriosis on Black women who already deal with societal ills and systemic racism and sexism associated with being both Black and a woman. Research grants and federal, state, and private funding should be dedicated to improvements in health care; public awareness;

and community, state, and federal resources devoted to Black women with endometriosis who also cope with the intersectional nature of being a Black woman in the United States. This recommendation is particularly relevant for Black women experiencing severe and incurable symptomology associated with endometriosis. Also, training programs should be established to educate health care providers and Black women about the importance of multiculturalism, the harm associated with SBWS, and the strong relationship between endometriosis, chronic pain (particularly CPP), and mental illness.

This research reveals multicultural sensitivity and knowledge about the relationship between endometriosis and mental illness to be paramount when treating Black women with endometriosis. In the absence of a universal health care system in the United States, doctors, physician’s assistants, psychologists, therapists, and other providers must work together to provide a more comprehensive approach to treatment and the continuity of care. By using pain indexes with Black women that measure their physical symptoms and mental distress, health care providers can become more aware of their pain, resulting in more patient-centered, holistic, adequate, and effective treatment. Lastly, health care providers should provide resources to Black women in their care so they do not feel misunderstood and ignored.

Moreover, they should do so while acknowledging how Black women are impacted by maladaptive behaviors related to the SBWS and mental health stigmas in the Black community. In addition, health care providers should consider creating safe spaces that are culturally sensitive, familiar, and comfortable for Black women that encourage them to focus on healing through self-expression instead of victim-blaming (see Bryant-Davis et al., 2016).

The womanist theory promotes Black women's wellness through developing environments that welcome their authenticity and empowers them. According to King (2003), womanism includes empowering Black women and accepting their various identities but resisting maladaptive schemas. As mentioned earlier in this study, Black women could benefit physically and emotionally from researchers, providers, and practitioners developing and implementing healthier coping mechanisms reflective of womanism to facilitate this population's resilience and resistance against generational, unhealthy SBWS coping mechanisms. These recommendations align with Black Feminist theory and the biopsychosocial treatment model because these theories consider the connectedness of mental health, physical illness, and social factors impacting Black women.

Additionally, the biopsychosocial model promotes the critical nature of collaborative pain management amongst mental health and other health care providers. This model is the kind of care that Black women need considering the oppressive nature of the SBWS and its dire impact on Black women's psychological and physical health.

Implications

This section will discuss its implications as they relate to the analytical findings and how those findings pertain to positive social change. The section will also discuss critical recommendations that could promote awareness and positive social change and how this body of work can facilitate awareness and change. This study has contributed to the existing gap in the literature on understanding the mental health of Black women who experienced endometriosis-related symptoms during COVID-19. Many of the study's findings aligned with the results of existing literature. However, some of the findings were unique. Regardless of the findings, the implications of this study address the challenges Black women have in the United States related to intersectionality, SBWS, endometriosis symptoms, and mental distress. The findings imply that COVID-19 did not impact the participants' quality of care other than posing an inconvenience due to the inaccessibility to appointments and extended emergency room visits.

On the contrary, most women felt that their level of care improved during COVID-19. To promote awareness of Black women's challenges (as described above), I plan to share this research with the participants and encourage them to share it with their providers and family members. I also plan to share this research with my providers, family members, SpeakEndo, Funding Hope, Endo Black, Incorporated, and other organizations that promote the cause of helping Black women who have endometriosis. I will share this research at Meet and Greets and other events in the future and set up tables promoting research, awareness, and psychotherapeutic intervention, such as mindfulness or Acceptance and Commitment Therapy, which help treat chronic pain.

As summarized above, the study found that more participants perceived their level of care to be better during COVID-19 for various reasons. However, this perception was mainly related to their engaging in more self-care and self-management activities, changing to alternative caregivers, and seeking psychotherapeutic treatment. The participants did not attribute their perceptions of having an adequate level of care during

COVID-19 to improvements in doctors' treatment, except for one participant who had complications related to contracting COVID-19 and multimorbidity. Most participants stated that inaccessibility to in-person appointments and long emergency room waits limited receiving the care they needed. During the interviewing and analytical process, it was clear that once the women began to explore what worked for them at home during COVID-19 restrictions, they began to feel that their care was better (compared to pre-COVID conditions. One participant emphasized that pre-COVID conditions did not allow her to pay attention to her body, pain, mental anguish, and other symptoms because she spent more time away from home.

Several participants mentioned that they began seeking mental health treatment during COVID-19 due to mental distress, citing illnesses such as anxiety and depression. However, when questioned about whether their providers helped them with their mental anguish, all reported that their providers did not support them with their mental health needs. Most participants also said they were unaware of the impact of endometriosis, mainly CPP, on mental health. This finding indicates that doctors are either unaware of this scientific reality or do not care enough to address it with their patients suffering from endometriosis pain. Also, the participants commented on their doctors being unsupportive, not validating their concerns or listening to them, and seeming incompetent or lacking knowledge about endometriosis and the best treatments for their presenting concerns. Participants also frequently mentioned how complex and misunderstood endometriosis is within their support groups and in other settings; one participant even said she feels that her doctor does not understand the illness.

All these findings indicate a need for more research on how endometriosis impacts Black women considering its complicated nature and the impact that the SBWS has on Black women’s ability to cope. The internalization of the SBWS has a detrimental effect on Black women’s daily lives and has been linked to depression (see Abrams et al., 2019). These women are also at risk for suicidality due to their tendency to be caretakers, regulate their emotions, and engage in self-reliance leading to depression (see Green, 2019). Again, this study found that all of the participants experienced at least four of the SBWS behaviors. This finding means that all eight of these women believe that they must suppress their emotions, resist feeling vulnerable, possess an intense motivation to achieve or succeed, or present an image of strength.

Notably, when responding to the five questions related to the SBWS, many women expressed the impact their mothers and other female elders had on their behaviors, implying that they modeled their behaviors. These findings, which include the participants’ feelings about being Black mothers, the only Black woman in the workplace, Black leaders, and Black women partners who do not want to burden their families with their pain, indicate that change is required to help Black women develop healthier thoughts, feelings, and behaviors. Therefore, this study’s findings align with existing studies that found that Black women must live with endometriosis issues while being “super” in various roles, such as mother, wife, and worker, and indicate that Black women need specialized care due to the intersectional nature of being a Black woman who internalizes racist and stereotypical roles while simultaneously being impacted by the SBWS behaviors and endometriosis symptomology (see Rea et al., 2020). The triangulation of gender, race, and socioeconomic factors adversely affects Black women's psychological health and their proneness to seeking health care (see Hamilton-Mason, 2009).

In light of this study's findings, providers should create treatment plans that facilitate more adaptive behaviors in the Black woman population and promote womanism and Black women's awareness of maladaptive schemas. They must acknowledge deficits in their care and treatment methods, receive proper multicultural or culturally sensitive training, incorporate an assessment of Black women's physical and mental pain in their intake process, and provide appropriate resources and referrals. Practitioners must take a holistic, preventative, and proactive approach addressing how chronic pain related to endometriosis can impact Black women's lives regarding their mental health and other factors so that Black women's needs can be met. Also, providers must engage womanism philosophies when treating Black women, realizing how the SBWS impacts Black women's quality of life. If these health care improvements are not developed, treatment for many Black women will remain ineffective. Black women will continue to exist in a generational and cyclical pattern of physical and mental pain that will be passed on to their daughters and granddaughters.

Conclusion

This study was designed to address a gap in current research related to exploring and gaining a deeper understanding of Black women's perceptions of their mental health while experiencing endometriosis-related symptoms during the COVID-19 pandemic. I sought to understand this phenomenon through eight women's narratives from their perspectives. I used a phenomenological approach to facilitate the documentation of rich and meaningful data resulting in a deep, contextual understanding of the participants' experiences. Currently, no existing studies address this topic with this population in the United States, so research of this nature is undeniably untapped; hopefully, it will be helpful.

After contemplating the research process, I realized that the women needed to be (and valued being) heard as much as I valued the nature of the research and their stories. Most overwhelmingly, I realized that despite endometriosis being a disease discovered in 1927, roughly 105 years ago, it is still an underfunded, under researched, misunderstood, and incurable disease that continues to impact Black women's lives adversely. Furthermore, the U.S. health care system remains the same despite much research and literature revealing that Black women are maltreated and suffer dire consequences due to racism and discrimination. Black women continue to be lost in a system that disproportionately leads to their mortality, morbidity, disability, and other conditions. This social problem persists today. Anderson et al. (2009), As-Sanie et al. (2019), Bonham (2001), Bougie et al. (2019), CDC (2005), Cleeland et al. (1997), Hoffman et al. (2016), Hollingshead et al. (2015), Jacoby et al. (2010), Mende-Siedlecki et al. (2019), Mossey (2011), Nelson (2002), and Shavers et al. (2010) are just a few researchers who have presented their findings that point to the same problem: The intersectionality of the Black woman in the American health care system perpetuating unequal treatment, sometimes mortality.

The participants referred to their doctors as lacking cultural competence, education, awareness, empathy, and support. Participants also recounted feeling isolated and alone in their pain in different settings, often unsupported. The women also discussed problematic deficits in the health care system, including insurance lapses, inadequacies, and a lack of research funding and resources to support Black women's needs related to endometriosis care. One woman commented on doing her research, sharing her research, and relying on support groups for support because she does not have confidence in her past and current care and her doctors' knowledge of endometriosis. The participant summarized her experiences with a complex and multifaceted statement as follows:

> There's no research, and then there's no funding to it, especially Black women who struggle with reproductive issues. I just think, to be honest, it needs a total makeover. But I think that what we can do from here is just fund more research and fund more resources that can help Black women outside of the hospital because, honestly, a lot of the health care, a lot of the doctors in the health care system aren't very helpful and only offer avenues of like surgery or medication, and a lot of times those communities, a lot of Black communities, don't have accessibility to even afford these solutions. So, it's kind of like you're just dangling, you know, help in front of someone and telling them they can't reach it. So, it's just, it's really like, it would take a whole rejuvenation of the whole health care system, really. But, yeah, I just think we need more resources outside of the health care system and more avenues (PRT8).

Moreover, the biopsychosocial treatment model would be advantageous in health care because it motivates interprofessional collaboration and teamwork in research and care, leading to effective and swift developments (see Havelka et al., 2009). This model considers Black women's physical, psychological, and social factors that affect each other while considering a variety of holistic approaches (i.e., pharmacological, surgical, and psychological techniques) to alleviate pain. It would be an ideal model for Black women who suffer from the SBWS behaviors.

Overall, I hope this body of research ignites passion and sparks motivation within the medical, mental health, and research communities leading to petitions and additional research funding and resources for Black women with endometriosis. Also, I have confidence that this study will inspire providers to adopt more culturally sensitive practices resulting in the restoration, rehabilitation, and resilience of Black women's health and more balanced and equitable health care settings. Lastly, I hope this study motivates pandemic procedure improvement so Black women can access doctors for face-to-face appointments to address their chronic pain and other symptoms. One participant remarked, "Yeah, I think definitely, by studies like this that are talking about like going further and talking to people. And being able to find out, hey, like, how do you function in a day because people think it's normal." Like her, I hope studies like this will make a positive difference.

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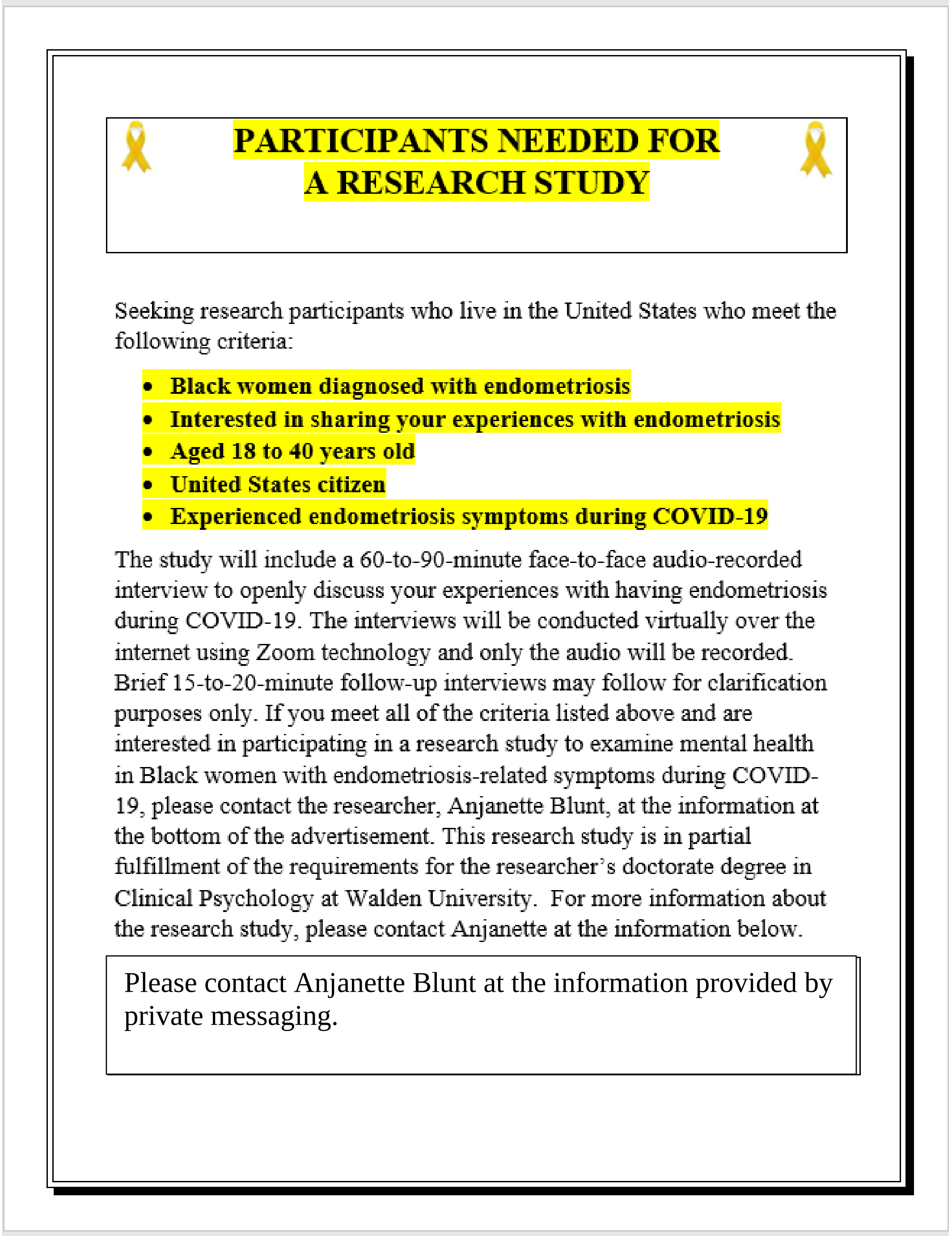
Appendix A: Participant Recruitment Advertisement



PARTICIPANTS NEEDED FOR A RESEARCH STUDY

Seeking research participants who live in the United States who meet the following criteria:

- **Black women diagnosed with endometriosis**
- **Interested in sharing your experiences with endometriosis**
- **Aged 18 to 40 years old**
- **United States citizen**
- **Experienced endometriosis symptoms during COVID-19**

The study will include a 60-to-90-minute face-to-face audio-recorded interview to openly discuss your experiences with having endometriosis during COVID-19. The interviews will be conducted virtually over the internet using Zoom technology and only the audio will be recorded. Brief 15-to-20-minute follow-up interviews may follow for clarification purposes only. If you meet all of the criteria listed above and are interested in participating in a research study to examine mental health in Black women with endometriosis-related symptoms during COVID-19, please contact the researcher, Anjanette Blunt, at the information at the bottom of the advertisement. This research study is in partial fulfillment of the requirements for the researcher's doctorate degree in Clinical Psychology at Walden University. For more information about the research study, please contact Anjanette at the information below.

Please contact Anjanette Blunt at the information provided by private messaging.

Appendix B: Semistructured Interview Questions

The purpose of this interview is to provide a safe, private, and confidential space to discuss your experience with having endometriosis symptomology during the COVID-19 pandemic. I am interested in your perceived level of medical and mental health care while having endometriosis during the COVID-19 pandemic and how having the illness during the COVID-19 pandemic and its restrictions might have impacted your overall health and level of care. The overarching topics that I will address include your lived experience as a Black woman with endometriosis (particularly during the COVID-19 pandemic), how you manage your endometriosis symptomology during the COVID-19 pandemic, and how you perceive your level of medical and mental health care that you have received for your endometriosis symptoms during the COVID-19 pandemic. The interview should take from 60 to 90 minutes to complete. Thank you, in advance, for taking the time and participation.

1. How old were you when you were diagnosed with endometriosis?
2. How has your experience with living with endometriosis been?
3. How has your experience with living with endometriosis during the COVID-19 pandemic been?
4. Were you diagnosed with endometriosis soon after the symptomology started?
5. What endometriosis symptoms have you experienced?
6. Do you think that your health care providers understand your endometriosis symptoms? Why or why not?
7. Has having endometriosis impacted any areas of your life, and if so, what areas has it impacted?
8. Do you feel that you have received adequate medical care for endometriosis-related pain before the COVID-19 pandemic? Why or why not?
9. Do you feel that you have received adequate medical care for endometriosis-related pain during the COVID-19 pandemic? Why or why not?
10. Have your endometriosis symptoms caused you mental distress, and if so, how?
11. Do you feel that doctors have considered your mental health needs when treating you for endometriosis? Why or why not?
12. Have you been diagnosed with any mental illness(es) related to your endometriosis pain or symptoms, and if so, what illness(es)?
13. Do you feel that you have received adequate mental health care for your endometriosis-related mental illness(es) during the COVID-19 pandemic? Why or why not?
14. How have you managed to deal with your endometriosis symptoms during the COVID-19 pandemic?

15. What is the most challenging thing about having endometriosis during the COVID-19 pandemic?
16. Do you feel obligated to present an image of strength in various settings? If so, please explain.
17. Do you feel the need to suppress your emotions? If so, please explain.
18. Do you feel like you resist vulnerability at times? If so, please explain.
19. Do you feel the obligation to help others? If so, please explain.
20. Do you feel an intense motivation to achieve or succeed? If so, please explain.
21. Do you feel like being a Black woman has impacted the quality of the medical and mental health care that you receive in the United States? If so, how?
22. Do you feel that the quality of your medical or mental health care can be improved? And if so, how?
23. If you had to describe living with endometriosis using one word, what would it be?

Appendix C: Demographic Survey

This survey is to collect demographic data and information about the research participants.

1) Age
    a. 18-22
    b. 23-27
    c. 28-32
    d. 33-37
    e. 38-42
2) Ethnicity
    a. Black or African American
    b. Native American
    c. African
    d. Middle Eastern
    e. White
    f. Native Hawaiian or Other Pacific Islander
    g. Hispanic Latino or Spanish Origin
    h. Other
3) Gender (assigned at birth)
    a. Male
    b. Female
    c. Other

4) Marital Status
    a. Married
    b. Single
    c. Divorced
5) Employment Status
    a. Full-Time Employment
    b. Part-Time Employment
    c. Unemployed
6) Location
    a. North America
    b. Central America
    c. South America
    d. The Caribbean
    e. European Union
    f. Eastern Europe
    g. Middle East
    h. Africa
    i. Oceania
7) Education
    a. Less than High School
    b. High School Graduate
    c. Vocational/Trade/Technical School

d. Some College
e. Bachelor’s Degree
f. Advanced Degree

Appendix D: Participant Interview Schedule

Participant Pseudonym	**Date of Interview**	**Time of Interview**
PRT1 (Participant 1)	Friday, 8/5/2022	10:30 a.m. EST
PRT2 (Participant 2)	Friday, 8/12/2022	2 p.m. EST
PRT3 (Participant 3)	Friday, 8/12/2022	7 p.m. EST
PRT4 (Participant 4)	Monday, 8/15/2022	1 p.m. EST
PRT5 (Participant 5)	Monday, 8/15/2022	7 p.m. EST
PRT6 (Participant 6)	Tuesday, 8/16/2022	12 p.m. EST
PRT7 (Participant 7)	Friday, 8/19/2022	7 p.m. EST
PRT8 (Participant 8)	Friday, 8/26/2022	11 a.m. EST