Psychobiological, Clinical, and Sociocultural Factors that Influence Black Women to Seek, Initiate, and Complete Treatment for Infertility: A Mixed Methods Study

by

Morine Cebert

Nursing
Duke University

Date:__________
Approved:

___________________________
Rosa Gonzalez-Guarda, Advisor

___________________________
Eleanor Stevenson

___________________________
Susan Silva

___________________________
Peggy Shannon-Baker

Dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Nursing of Duke University

2020
ABSTRACT

Psychobiological, Clinical, and Sociocultural Factors that Influence Black Women to Seek, Initiate, and Complete Treatment for Infertility: A Mixed Methods Study

by

Morine Cebert

Nursing
Duke University

Date: __________
Approved:

___________________________
Rosa Gonzalez-Guarda, Advisor

___________________________
Eleanor Stevenson

___________________________
Susan Silva

___________________________
Peggy Shannon-Baker

An abstract of a dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Nursing
Duke University
2020
Abstract

Black women in the U.S. have twice the prevalence of infertility (14%) than non-Hispanic White women (7%) yet are twice as less likely to seek initial evaluation for infertility. Disparities in infertility treatment use among Black women are crucial to address in order to promote health and wellness in this population. Childbearing is a culturally central component of Black families and Black women with infertility experience notable alterations to their self and gender identity, high levels of isolation, silence, and negative medical experiences related to their fertility status. Despite these negative experiences among Black women, the literature fails to highlight reasons for lower uptake of infertility treatment beyond highlighting the sociodemographic characteristics of those who seek, initiate, and complete treatment as mainly affluent, highly educated, and older Non-Hispanic White women. Research on the health seeking process for Black women with infertility is scarce and provide incomplete understanding of their reproductive experiences. Since little is known about what factors influence the processes of seeking, initiating, and completing treatment for infertility for Black women, the purpose of this dissertation was to generate knowledge of the multi-dimensional influences that Black women may experience during the their journey to family building.
The aim of this dissertation study was to understand the psychobiological, clinical, and sociocultural factors that influence Black women’s decisions to seek, initiate, and complete the recommended treatment plan for infertility within three different chapters. Chapter 2 reviewed the state of the science regarding the psychobiological, clinical, and sociocultural factors that influenced women in the U.S to seek treatment for their infertility symptoms and experiences. Chapter 3 analyzed and described psychobiological, clinical, and social data collected from a retrospective cohort chart review that examined 391 Black women who sought a reproductive endocrinology evaluation and determined what factors influenced initiation and completion of the recommended treatment plan for infertility. In, Chapter 4, quantitative data from Chapter 3 was merged with qualitative data from 13 semi-structured interviews in a convergent parallel mixed methods study to provide a comprehensive understanding of what psychobiological, clinical, and sociocultural experiences influenced Black women to seek and initiate treatment for infertility.

Psychobiological, clinical, and sociocultural factors are associated with seeking, initiating, and completing infertility treatment among Black women. Multi-dimensional barriers across these domains influence the entire health seeking process for women causing delays in access, reduced uptake in treatment, and ultimate completion of treatment. Black women would benefit from future research that target modifiable factors by way of intervention development and policy modifications that increase safe,
affordable, and culturally sensitive access to reproductive endocrinology services to reduce these disparities affecting Black women with infertility.
Dedication

I dedicate this dissertation to my grandmother, Merita Saintval. My grandmother never had the chance to learn how to read or write. Yet, she prayed for me. With purpose and vigor.

I dedicate this dissertation to my mother, Saintania Cebert. My mother also never had the chance to complete a formal education. Yet, she worked tirelessly on my behalf. With love and unending sacrifice.

I dedicate this dissertation to my father, Moresse Cebert. My father talked endlessly about his desires to go to college one day. Yet, he spent his time instilling within me the importance of education. With enthusiasm and persistence.

I dedicate this dissertation to my spiritual parents, Eric & Mimi Greaux. They never had the opportunity to birth a daughter. Yet, they loved me as if I was their own. With good food and constant laughter.

I dedicate this dissertation to all my family and friends. They experienced my absence from celebrations and frustrations with school. Yet, they cheered me on until I reached the finish line. With sweet messages and tender hearts.

Thank you, Jesus, my cup runneth over.
Contents

Abstract ........................................................................................................................................iv

Dedication ...................................................................................................................................... vii

List of Tables .................................................................................................................................. xiii

List of Figures ................................................................................................................................... xv

Acknowledgements .......................................................................................................................... xvi

1. Introduction ................................................................................................................................. 1

1.1 Definitions & Prevalence ............................................................................................................. 1

1.2. Effects of Infertility .................................................................................................................. 2

1.3 Infertility Treatment Use, Options, and Advantages of Use .................................................. 3

1.4 Disparities in Reproductive Endocrinology ............................................................................. 4

1.5 Health Seeking Patterns in Black Women ................................................................................. 6

1.5.1 Treatment Seeking ................................................................................................................. 7

1.5.2 Treatment Initiation ............................................................................................................... 9

1.5.3 Treatment Completion .......................................................................................................... 11

1.5.4 Gaps in the Literature .......................................................................................................... 13

1.6 Theoretical Framework ............................................................................................................. 14

1.6.1 Symptom Definition ............................................................................................................. 15

1.6.2 Illness-Related Shifts in Role ............................................................................................... 16

1.6.3 Lay Consultation and Referral ............................................................................................ 16

1.6.4 Treatment Actions .............................................................................................................. 17
1.6.5 Adherence ........................................................................................................... 18

1.7 Aims of the Dissertation Manuscript ..................................................................... 18

2. Psychobiological, Clinical, and Sociocultural Barriers and Facilitators to Treatment Seeking for Infertility Among Women in the United States .................................. 22

2.1 Introduction ............................................................................................................ 22

2.1.1 Theoretical Framework ...................................................................................... 24

2.2 Methods ................................................................................................................ 27

2.2.1 Search Strategy .................................................................................................. 27

2.2.2 Inclusion Criteria ............................................................................................... 28

2.2.3 Data Extraction & Synthesis: ............................................................................. 29

2.3 Results .................................................................................................................... 37

2.3.1 Sample Characteristics ...................................................................................... 37

2.3.2 Symptom Definition .......................................................................................... 39

2.3.3 Role-Illness Change ......................................................................................... 40

2.3.4 Lay Consultation & Referral ............................................................................. 40

2.3.5 Treatment Actions .............................................................................................. 42

2.4 Discussion .............................................................................................................. 43

2.4.1 Strengths and Limitations ................................................................................ 46

2.4.2 Implications ....................................................................................................... 47

2.4.3 Conclusions ....................................................................................................... 49

3. Psychobiological, Clinical, and Social Factors Associated with the Initiation and Completion of the Recommended Treatment Plan for Infertility among Black Women .50

3.1 Introduction .......................................................................................................... 50
4.2.1 Design ..................................................................................................................89
4.2.2 Setting....................................................................................................................89
4.2.3 Samples..............................................................................................................90
4.2.4 Quantitative Measures & Data Collection .........................................................91
4.2.5 Qualitative Recruitment & Data Collection .......................................................93
4.2.6 Quantitative Data Analysis ................................................................................97
4.2.7 Qualitative Coding and Analysis .......................................................................97
4.2.8 Integration Analysis ..........................................................................................100
4.3 Findings ..................................................................................................................101
4.3.1 Quantitative Results ..........................................................................................101
4.3.2 Qualitative Results ............................................................................................105
  4.3.2.1 Treatment Seeking .......................................................................................106
  4.3.2.2 Treatment Initiation ....................................................................................114
4.3.3 Integration ..........................................................................................................126
  4.3.3.1 Treatment Seeking .......................................................................................126
  4.3.3.2 Treatment Initiation ....................................................................................131
4.4 Discussion ..............................................................................................................136
  4.4.1 Limitations ......................................................................................................140
  4.4.2 Future Directions ...........................................................................................140
5. Conclusions ..............................................................................................................142
  5.1 Treatment Seeking ............................................................................................143
  5.2 Treatment Initiation ............................................................................................145
5.3 Treatment Completion........................................................................................................146
5.4 Strengths ..........................................................................................................................147
5.5 Limitations ......................................................................................................................149
5.6 Future Directions ............................................................................................................150
5.6.1 Implications for Nursing Practice ..............................................................................151
5.6.2 Research ....................................................................................................................152
5.6.3 Policy ..........................................................................................................................154
5.7 Conclusion ......................................................................................................................156

Appendix A. Protocol for Obtaining Variables for Retrospective Chart Review ...........157
Appendix B. Blank Demographic Data Survey .................................................................170
Appendix C. Interview Script Initiated ..............................................................................172
Appendix D. Interview Script Did Not Initiate .................................................................174
References ...........................................................................................................................176
Biography .............................................................................................................................191
List of Tables

Table 1. Sample of Systematic Review (N=22) ................................................................. 31

Table 2: Psychobiological, Clinical, and Social Measures ................................................. 60

Table 3: Patient Characteristics for Infertility Sample and Treatment Initiation Subsample ................................................................................................................................. 66

Table 4: Psychobiological, Clinical, Social Factors (N=391) ............................................. 67

Table 5: Fertility Treatment Outcomes ............................................................................... 69

Table 6: Treatment Initiation: Bivariate Logistic Regression Results (N=391) ............... 71

Table 7: Psychobiological, Clinical, and Social Measures for Retrospective Chart Review ................................................................................................................................. 91

Table 8: Semi-structured Interview Protocol Sample Questions ....................................... 96

Table 9: Psychobiological, Clinical, Social Factors of Black Women who Sought Treatment (N=391) ........................................................................................................... 102

Table 10: Treatment Initiation: Bivariate Logistic Regression Results (N=391) ............. 103

Table 11: Individual Features of Interview Participants (N=13) ....................................... 105

Table 12: Psychobiological, Clinical, and Sociocultural Barriers and Facilitators to Treatment Seeking ...................................................................................................................... 106

Table 13: Psychobiological, Clinical, and Sociocultural Barriers and Facilitators to Treatment Initiation ...................................................................................................................... 114

Table 14: Joint Data Display for Psychobiological, Clinical, and Sociocultural Characteristics of Black Women Who Seek Treatment ................................................................. 126

Table 15: Joint Data Display for Psychobiological, Clinical, and Sociocultural Influences on Treatment Initiation ........................................................................................................... 131
List of Figures

Figure 1: PRISMA Flow Diagram ........................................................................................................... 37

Figure 2: Health Seeking Process of Black Women Who Undergo Evaluation for Infertility and Decide to Initiate Infertility Treatment................................................................. 53

Figure 3: Process for Obtaining the Infertility Sample (N=391).............................................................. 58

Figure 4: Health Seeking Process of Black Women Who Undergo Evaluation for Infertility and Decide to Initiate Infertility Treatment................................................................. 84
Acknowledgements

This dissertation was supported by the Robert Wood Johnson Foundation Future of Nursing Scholars Program, the National Institute of Nursing Research of the National Institutes of Health under Award Number NR018790-01A1. The study was also supported by a grant from the Duke University School of Nursing PhD Student Pilot Fund. Additional training for the study was also made possible by the Graduate Student Training Enhancement Grant through the Office of the Provost at Duke University.

I would like to acknowledge Samia Abdelnabi and Elise Mantell for their work in aiding in screening and reviewing for Chapter 2. I would like to acknowledge the Shady Grove Fertility Research Team especially Jennifer Wood, Tasha Newsome, Samad Jahandideh, Renee Hart, Sally Villabolos, Joshua McKeeby, Katherine Devine, and all those who helped make data collection and quality assurance possible. Also, thanks to Dominique Bulgin for her time and talent in helping me code in Chapter 4. Thanks to Toniya Brown, Bianca Rochelle, and Ethan Bott for helping me review transcripts.

Lastly, my amazing committee. Eleanor Stevenson, Rosa Gonzalez-Guarda, Susan Silva, and Peggy Shannon-Baker had an unrelenting commitment to my personal and professional well-being. I truly could not have done it without them.
1. Introduction

1.1 Definitions & Prevalence

Infertility is a disease of the reproductive tract where those affected experience the inability to conceive or maintain a pregnancy to full term after 12 months of regular unprotected heterosexual intercourse for women under 35 years old and six months for women over 35 years old (American Society of Reproductive Medicine [ASRM], 2019; World Health Organization, [WHO] 2019). Infertility is commonly classified as primary or secondary infertility. Primary infertility is the inability to conceive in the previously discussed timeframes for a first livebirth, whereas secondary infertility is the inability to conceive in the same period after already having one or more livebirths.

Globally, 186 million women and families are affected by infertility and causes can be singular or multifactorial (Vander Bght & Wyns, 2018). Within the United States, estimates show that up to 15% of women ages 15 to 44 years old experience infertility, and factors contributing to infertility can be due to delayed childbirth, older age, and other diseases that reduce fertility or childbearing capacity (Vander Bght & Wyns, 2018; Centers for Disease Control and Prevention [CDC], 2015). Clinically, causes of infertility are often categorized as female factor, male factor, combined male and female factor, and unexplained infertility. Female factor infertility can manifest as diminished quality of oocytes (female gametes), hormonal
imbalances that lead to abnormal ovulation, tubal disorders, or uterine factors (Breitkopf & Hill, 2019). Male factor infertility accounts for 40-50% of all cases of infertility. Male factor infertility can be caused by poor semen quality secondary to either erectile disorders, genetic anomalies, toxic environment exposure, or other factors (Stevenson et al., 2016). Further, unexplained infertility is the absence of an identifiable source affecting conception. Unexplained infertility occurs in about 30% of all couples presenting with impaired fertility symptoms (Breitkopf & Hill, 2019).

1.2. Effects of Infertility

It is well-documented that persons dealing with infertility experience negative psychological, biological, financial, social, and cultural consequences related to their diagnosis (Hocaoglu, 2018; Karaca, Yavuzcan, Batmaz, Cangür, & Çalışkan, 2019). These experiences have often been discussed as the most stressful aspect of the disease process because purposeful family building is inhibited. Psychologically, women with infertility are known to have higher rates of depression, anxiety, distress, loss of control, and lower quality of life than women without infertility (Williams, 1997; Cousineau & Domar, 2017; Domar, Zuttermeister, & Friedman, 1993). Women who experience infertility often have underlying or co-occurring biological disorders that influence the health of their reproductive organs, such as uterine, endocrine, and other infectious disease pathologies (Silvestris, de Pergola, Rosania, & Loverro, 2018). Also, this population of women struggle with
their social identities as they find difficulty in accepting an infertility diagnosis and challenges with achieving biological motherhood (Loftus & Namaste, 2011). However, this effect on social identities is known to differ among varying cultural contexts, where effects can be deleterious especially in more pronatalist contexts (Sexty et al., 2016). As the prevalence of infertility remains an issue for many women in the United States, there is a growing need for safe, accessible, and affordable options for infertility treatment options to reduce the devastating sequela of this damaging disease.

1.3 Infertility Treatment Use, Options, and Advantages of Use

In the United States, the CDC estimates that 7.4 million women in childbearing ages 15-44 have used some type of infertility services for family building (CDC, 2015). However, this value is not reflective of all women who experience infertility. National surveys reveal only 12% of women who experience infertility will seek treatment (Kessler et al., 2013), whereas globally, upwards of 50% of women who meet criteria for infertility seek treatment (Chandra, Copen, & Stephen, 2014).

Infertility treatment options have advanced substantially since the advent of the first successful in vitro fertilization baby, Louise Brown, in 1978 (Kamel, 2013). These treatment options are generally grouped into two categories that range in invasiveness: in vivo fertilization or in vitro fertilization (IVF) (Stevenson, Hershberger, & Bergh, 2016). In vivo fertilization treatment modalities attempt for
conception to occur within the fallopian tubes, whereas conception for IVF occurs within a controlled clinical laboratory environment performed and supervised by embryologists. Low invasive options include general fertility counseling such as proper timing of intercourse and lifestyle modifications such as cessation of alcohol, nicotine, and caffeine intake along with weight loss. Higher invasive options include controlled ovarian hyperstimulation with the use of oral- or injection-based medications in conjunction with timed intercourse or intrauterine insemination.

Treatment options for infertility vary in duration, cost, and success rates. Nevertheless, the advantages of infertility treatment has well documented advantages even if treatment is unsuccessful. There have been documented positive outcomes associated with prompt and successful treatment of infertility. The positive outcomes include increased self-confidence, decreased stress, and increased joy (Ranjbar, Akhondi, Borimnejad, Ghaffari, & Behboodi-Moghadam, 2015) along with increased gratitude (Ladores & Arojan, 2015). Similarly, women who experienced stress and anxiety during infertility treatment often experienced progressive improvements with mental health markers after successful conception (Velikonja, Lozej, Leban, Verdenik, & Bokal, 2016).

1.4 Disparities in Reproductive Endocrinology

Despite advances in infertility treatments and known benefits of use, there are numerous groups who historically and at present do not benefit from these
clinical innovations. Black women in the U.S. have twice the prevalence of infertility (14%) than non-Hispanic White women (7%), yet are two times less likely to seek treatment (Chin et al., 2015; Dieke et al., 2017; Quinn, & Fujimoto, 2016; Shapiro et al., 2017; Chandra et al., 2013). Ceballo et al. (2015) suggest that Black women experience great negative views of self and self-identity, high levels of isolation and silence within social circles, and negative experiences with medical personnel when attempting to address their symptoms of infertility. However, the vast majority of the empirical research that examines factors that promote infertility treatment initiation and completion has largely focused on highly educated, married, White women and is virtually non-existent for Black women in the United States (Ceballo et al., 2010).

Infertility and the consequences of infertility become particularly crucial to address in the Black community as childbearing is a culturally central component of Black families (Hill, 2001); however, the literature does not seem to provide as in depth and comprehensive representations of this group of women’s experiences within the clinical environment. Numerous studies have described many sociodemographic factors associated with lower treatment utilization. The typical characteristics of those who seek, utilize, and complete treatment for infertility are described as older women who are Non-Hispanic White, with high socioeconomic status, and have high levels of education (Chin et al., 2015; Quinn & Fujimoto, 2016;
Dieke, et al., 2017; Shapiro et al., 2017). Although costs may contribute to decreased treatment seeking, in the 16 states adopting state mandated fertility treatment coverage (Schmidt, 2007; Buckles, 2013; Mattocks et al., 2015), Black women continue to lag in infertility utilization despite reduced barriers to access. This suggests that cost may not be the only factor affecting Black women as they decide whether to seek clinical evaluation with reproductive endocrinology specialists, initiate and ultimately complete the recommended treatment plan.

1.5 Health Seeking Patterns in Black Women

The health seeking process has been defined as the set of decisions and actions undertaken by individuals who perceive themselves to have a problem or illness for the purpose of finding an appropriate remedy (Oberoi et al., 2016). It is well established that no matter the disease process, from symptom onset to treatment initiation, numerous contextual factors play a role in decisions to undergo evaluative services and accept the treatment plan prescribed by the consulting practitioner. There are minimal studies that examine the health seeking patterns of Black women with infertility in order to explain the disparities seen in treatment utilization. However, based on studies that examine Black women’s experiences with other diseases, the literature suggests there are multi-factorial influences that affect several decisions and actions along the health seeking process, especially during
early treatment seeking, initiation of recommended treatment, and ultimate completion of the treatment plan in its entirety.

1.5.1 Treatment Seeking

For this dissertation, treatment seeking was defined as the process in which women make entry into the clinical environment to receive formal evaluation for their infertility (Wang et al., 2007). Although the evaluative process can be tailored to the individualistic needs of patients and their families, clinical guidelines suggest that prompt evaluation is a crucial aspect of successful treatment (Crawford & Steiner, 2015). Clinical evaluations that occur during the treatment seeking phase can be non-invasive such as taking complete histories or obtaining genetic counseling (Stevenson et al., 2016). However, the appropriate assessment of infertility for heterosexual couples involves in-depth diagnostic testing of blood and semen specimens along with advanced imaging of female and male anatomy (Stevenson et al., 2016; Breitkopf & Hill, 2019). Upon completion of the initial assessment, providers should present a comprehensive description of results, assign applicable diagnoses, and offer preliminary suggestions of a treatment protocol that fits the needs of the patient.

The facilitators and barriers of treatment seeking patterns of Black women within reproductive endocrinology has not been well-explored. However, the scientific literature suggests that Black women in the U.S often experience several
barriers to treatment seeking causing delayed presentation for other disease processes, including but not limited to breast cancer (George et al., 2015), eating disorders (Ali et al., 2017), HIV (Ransome et al., 2018), and mental health disorders (Lara-Cinisomo et al., 2018) among others. Factors associated with late presentation were ascribed to patient, clinic, and health system factors that limited early evaluation and identification. For example, in George et al. (2015) Black women were more likely to self-identify breast cancer than White women whose breast cancers were detected earlier through routine screenings by providers. Previously, Black women with breast cancer have been documented to delay treatment seeking most often due to fears about treatment risks and negative attitudes towards general practitioners (Bish, Ramirez, Burgess, & Hunter, 2005). Also, delays in Black women’s presentation for evaluation in eating disorders were found to be associated with family member and physicians failing to view Black women for having complaints that were clinically concerning (Ali et al., 2017). Disease-related stigma and limited education were also associated with delayed presentation for evaluation (Ransome et al., 2018; Lara-Cinisimo et al., 2018).

Similarly, facilitators for early treatment seeking for Black women seeking treatment for their diseases are also multi-factorial. Black women with chronic diseases engaged in treatment seeking if they had increased perceived social support and decreased stigma, especially those experiencing HIV (Rao et al., 2018). Also,
after a major announcement from a celebrity influencer, Black women had reduced stigma and an increased likelihood of seeking cancer and genetic screening (Noar, Althouse, Ayers, Francis, & Ribisl, 2015). Further, having a trusted healthcare provider and welcoming supportive staff have also been facilitators to prompt presentation for prenatal care in certain groups of Black women in the U.S (Mazul et al., 2017).

1.5.2 Treatment Initiation

For this dissertation, treatment initiation was defined as the decision to agree and deliberately implement the steps of a recommended treatment protocol at the discretion and supervision of the reproductive endocrinology team (Rivet Amico, 2011). As discussed previously, treatment protocols for infertility can range in cost, invasiveness, and timing (Stevenson et al., 2016). However, women and their families have several educational, psychosocial, economic, and physiological considerations that may influence their decisions of whether to initiate the recommended treatment plan. These include being understanding of success rates, costs, time commitment, complexity of protocol, and possible adverse reactions to treatment medications (Stevenson et al., 2016).

Facilitators and barriers to treatment initiation for Black women within reproductive endocrinology has not been comprehensively explored. However, like in infertility, Black women are known to experience higher rates of disease and low
rates of utilization in other diseases, including but not limited to bariatric surgical care (Moore et al., 2017), women’s cancers (Matsagani & Golden, 2015), and mental health disorders (Watson-Singleton, 2017). It is well-known that medical mistrust and discriminatory practices within the healthcare environment has influenced uptake of medical services among all Black populations in the U.S (Cueva et al., 2016). Black women who did not undergo bariatric surgery found that they had limited knowledge of surgical interventions, desired alternative methods, and had little social support regarding treatment (Moore et al., 2017). Financial barriers examined in other diseases has shown that Black women may underutilize services due to inadequate (not absent) insurance coverage or because they are diagnosed at advanced stages of disease requiring more invasive therapies not covered by insurance (Matsagani & Golden, 2015). In similar circumstances, Black women continue to show low rates of treatment uptake/utilization of treatment plans for mental health disorders even in the presence of health insurance (Watson-Singleton, 2017). These examples show that there may be other reasons beyond insurance ownership that affect treatment utilization. Although this study will examine factors beyond insurance, I acknowledge there remains a need for expansive reform to insurance and healthcare costs to reduce the burdens of social determinants of health that often limit uptake of quality services in numerous disease process affecting Black communities (Noonan et al., 2016).
Some studies have identified several facilitators that promote service utilization to prevent or reduce the effects of a disease among Black women. Black women who had increased knowledge of treatment protocols were more willing to utilize health care services to obtain pre-exposure prophylaxis for HIV prevention (Ojikutu et al., 2018) and medication to reduce symptom burdens for systemic lupus (Twumasi et al., 2019). Twumasi et al. (2019) also found that good communication between provider and patients led to improved self-management of treatment protocols. Finally, a systematic review of qualitative studies showed that social networks positively increased the utilization of cancer screening services among Black women (Hoffman-Goetz et al., 2014).

1.5.3 Treatment Completion

Treatment completion has been defined as the decision to complete all necessary steps and actions required to fulfill the requirements of the entire recommended treatment protocol at the discretion and supervision of the reproductive endocrinology team (Bryan et al., 2012). Within the current reproductive endocrinology research, this decision point has often been explored as treatment discontinuation. Reasons for not completing treatment have been reported as increased psychological burden, marital conflict, and perceptions of treatment futility (Walschaerts et al., 2013; Lande et al., 2015). Further, a systematic review suggest other reasons can be poor response to
treatment medications, pursuing treatment elsewhere, or reduced desires for parenthood (Gameiro et al., 2012).

Like treatment seeking and treatment initiation, facilitators and barriers to treatment completion have not been comprehensively explored in Black women experiencing infertility. The literature that examine treatment completion within other diseases processes among Black women has also detailed multi-factorial influences. The treatment completion patterns that have been explored in Black women, include but are not limited to those receiving antiretroviral therapy (Bogart et al., 2016), treatment for hypertension (Greer & Ostwald, 2015), and chemotherapy for breast cancer (Wells et al., 2015; Wheeler et al., 2019). The literature suggests barriers to completing treatment for Black women can be attributed to medical mistrust for the patient and within their social peers (Bogart et al., 2016). Further, negative side effects to therapies, depressive symptoms, and limited transportation issues have also been found to be barriers in treatment completion (Wells et al., 2015; Wheeler et al., 2019).

However, facilitators to treatment completion for Black women with hypertension was found to be largely influenced by support from community groups and increased knowledge of disease process (Greer et al., 2015). Also, Black women who had providers who used culturally relevant approaches and shared decision making were more like to adhere to treatment plans (Gaston, 2013). Further, motivational interviewing and culturally appropriate story telling were found to improve medication
adherence for women infected with HIV (Holstad et al., 2011) and hypertensive disorders (Houston et al., 2011).

1.5.4 Gaps in the Literature

Infertility is a devastating disease that presents with numerous consequences affecting the overall health and quality of life of women as they seek to intentionally build families. The current needs of Black women in the U.S. who are dealing with this disease are unknown despite documented disparities in disease prevalence and treatment utilization. Using the literature that highlights the numerous barriers and facilitators to health seeking among Black women with other disease processes, it would be appropriate to suggest that the health seeking experiences for Black women with infertility may also differ than other racial and ethnic groups with similar diagnoses. This dissertation posits that there may be a myriad of undocumented factors that lead to the stark disparities in treatment seeking, utilization, and adherence. Due to shortage of studies that examine the health seeking patterns of Black women experiencing infertility, this dissertation seeks to provide a comprehensive description and understanding of these factors that influence Black women in the U.S. as they seek, initiate, and complete the recommended treatment plans for infertility.
1.6 Theoretical Framework

The theoretical framework guiding this dissertation was largely adapted from the Chrisman Health Seeking Process Model (1977). The Chrisman (1977) process incorporates five conceptual components: symptom definition, illness-related shifts in role behavior, lay consultation and referral, treatment actions, and adherence. The domains represent patterns an individual experiences as they consider seeking, initiating, and completing interventions to address their health concerns. It posits that before a person seeks treatment, they must be aware of and hold certain beliefs about their symptoms, the symptoms must have some effect on their role and/or behaviors, and the consequences of the beliefs and perceptions influence who and how consultation is initiated. Once disclosure or consultation occurs, the preceding factors continue to play a role as the individual decides to initiate and complete treatment.

The Chrisman (1977) model provides an ideal framework for this study as it merges concepts from prominent conceptual models and frameworks to help scientists understand potential factors that influence medical behaviors, decisions, and perceptions of diverse groups. His model incorporates key elements of the psychobiological experience found in Roy’s Adaptation model (Shah, Abdullah, & Khan, 2015) and the Health Belief Model (Skinner et al., 2015), while highlighting the impact that the clinical healthcare environment poses on healthcare utilization in
Anderson’s model (Phillips et al., 1998). Finally, the multidimensionality of Chrisman’s model also encapsulates the complex and multi-layered sociocultural effects surrounding treatment seeking found in Bronfenbrenner’s Socioecological Model (Kilanowski, 2017). Each step along Chrisman’s (1977) health seeking chain represents numerous opportunities for barriers or facilitators to impact a person’s health seeking behavior and decision-making, exposing how these psychobiological, clinical, and sociocultural concepts act synergistically along the continuum of treatment seeking. Each of the domains are discussed below.

1.6.1 Symptom Definition

Symptom definition refers to the person’s perception of an illness or condition that affects whether a person seeks treatment or not (Chrisman, 1977). Symptom definition seeks to define how the person may perceive the illness as a danger or disability. Dangers include direct implications of having the disease, while disability explores the direct impact that inhibits life functioning. Symptom definition can be measured in the context of infertile women by measuring perceptions, knowledge, or awareness of the infertility disease state and how that may or may not correlate with increased treatment seeking. Further, this could be measured by examining the influences of the amount of time women wait to seek treatment for their infertility. Elements of symptom definition were used to synthesize findings in Chapter 2 and were discussed in Chapters 3 and 4.
1.6.2 Illness-Related Shifts in Role

Chrisman (1977) describes illness-related shifts in role behavior as an important factor leading to treatment seeking due to sociocultural influences. One may see that they cannot fulfill their role and therefore is further motivated to seek care. For example, a wife’s role is changed when she conceptually becomes an “infertile wife,” prompting treatment seeking. This area is measured by looking at culturally important roles that are affected by infertility such as personal desires to have children, partner mandates, or level of paternalistic society mandates. Elements of illness-related shifts in roles were used to synthesize findings in Chapter 2 and themes of this domain were explored in Chapter 4.

1.6.3 Lay Consultation and Referral

Lay consultation and referral refer to the individual who begins contacting members of their social network or the formal healthcare system to help with their illness or condition (Chrisman, 1977). This part in the process can vary person to person; however, aligned values will influence to whom and where consultation is sought along with the predisposing effects potentiated by the experiences during the symptom definition and role shift phases. Chrisman characterizes this approach as either parochial or cosmopolitan. The parochial approach is categorized as more traditional where a woman would connect with inner circles first, seeking support from peers. Looking beyond those spheres of influence due to either preference or
circumstance would then classify those who explore broader avenues of referral to the medical and clinical environment as cosmopolitan. This area of the model can be measured by understanding the influences and interactions with social support systems with regard to seeking infertility care. Similarly, this can be measured as the outcomes of the clinical assessment as evidence of consultation and referral. Elements of lay consultation and referral were used to synthesize findings in Chapter 2 and themes of this domain were explored in Chapter 3 and Chapter 4.

1.6.4 Treatment Actions

Finally, treatment actions examine broadly what treatment a woman undergoes and from where these directives originated, either personally or from outside sources (Chrisman, 1977). There are four treatment types: (1) activity alterations, (2) application or ingestion of substances, (3) verbal or ritual behaviors, and (4) physical interventions of the body. The treatment types can be classified under five treatment sources: (1) formal health professions, (2) licensed health practitioners, (3) alternative practitioners, (4) lay consults, and (5) self. Treatment actions were measured in Chapter 3 and Chapter 4 through detailing the recommended treatment plan and describing the population of who initiated treatment and detailing factors influencing those decisions.
1.6.5 Adherence

Adherence measures the degree to which the sick person acts upon treatment advice. Chrisman (1977) describes the domain of adherence to be very broad and influenced by many factors. The variability of adherence is measured as the degree to which advice is acted upon, partially or wholly, ranging from nearly total adherence to none. This process can be largely influenced by the provider-patient relationship and can highlight perceived power dynamics along with the resources the provider gives to the health seeker to achieve wellness. For this study, the domain of adherence was explored as treatment completion in Chapter 3 and explored in Chapter 4.

1.7 Aims of the Dissertation Manuscript

When understanding the multi-dimensionality of health seeking for Black women, this dissertation study posits there will be multifactorial influences that affect Black women’s experiences as they seek reproductive endocrinology evaluation and make decisions to initiate and complete the recommended treatment plan. The literature currently provides no empirical evidence of these factors. This study will provide a foundation for future efforts to bridge the gap between documented health disparities affecting Black women with infertility towards the development of interventions and policies to address these issues. The literature currently fails to describe what interventions will improve self-management
strategies of modifiable factors that may be inhibiting Black women to seek evaluation, initiate, and complete treatment. Furthermore, to the best of my knowledge, there is no study that identifies the challenges that Black women face with infertility treatment utilization and whether these experiences may be negatively influenced by other social determinants of health. Researchers and clinicians could use the findings of this dissertation to begin understanding the needs of Black women who seek treatment to improve their clinical experiences that could potential reduce the deleterious psychological, biological, social, and cultural consequences of infertility. Therefore, the aims of this dissertation study were to understand the psychobiological, clinical, and sociocultural factors that influence Black women’s decisions to seek, initiate, and complete the recommended treatment plan for infertility.

The dissertation aim was carried out in the following ways:

**Chapter One** introduced the problem and significance of infertility and the known effects on Black women. It further discussed the limited knowledge the literature provides on the health seeking experience of Black women who struggle with infertility. Finally, this chapter provided a comprehensive description of the theoretical framework guiding the dissertation study.

**Chapter Two** reviewed the state of the science regarding the psychobiological, clinical, and sociocultural factors that influenced women in the
U.S. to seek treatment for their infertility symptoms and experiences by conducting a systematic review of the current literature utilizing multiple large databases.

Chapter Three described the psychobiological, clinical, and social factors of 391 Black women who sought reproductive endocrinology evaluation and determined what factors influenced initiation of the recommended treatment plan for infertility through a retrospective cohort analysis. This study in chapter three also explored factors that influenced completion of the infertility treatment plan among those who began treatment. The primary outcome was initiation of infertility treatment within three months of the reproductive endocrinology evaluation. The secondary outcome was completion of the infertility treatment plan in its entirety. Characteristics of those who initiated and completed the proposed treatment plan for infertility were discussed.

The specific aims of Chapter Three were to:

Aim 1. Describe psychobiological, clinical, and sociocultural factors among Black women who sought evaluation for infertility by a reproductive endocrinology specialist.

Aim 2. Determine what psychobiological, clinical, and social factors were associated with initiation of the recommended treatment plan for infertility among Black women who underwent a reproductive endocrinology evaluation.
Aim 3. Explore psychobiological, clinical, and social factors associated with completion of the recommended treatment plan for infertility among the Black women who initiated.

Chapter Four provided a comprehensive description of what psychobiological, clinical, and sociocultural factors acted as barriers or facilitators to seeking and initiating treatment of the recommended after a reproductive endocrinology evaluation. This was achieved by conducting a convergent parallel mixed methods study that integrated the findings from the retrospective chart review in Chapter 3 and semi-structured interviews with Black women who sought treatment for their infertility.

The aim was to:

Integration Aim. Integrate results and themes identified from quantitative and qualitative data to provide a comprehensive multidimensional description and conceptualization of the psychobiological, clinical, and sociocultural experiences of Black women who seek and initiate treatment for infertility.

Chapter Five provided a detailed synthesis and summary of findings and included a comprehensive description of future implications and recommendations for policy, practice, and research related to treatment decision making among Black women experiencing infertility.
2. Psychobiological, Clinical, and Sociocultural Barriers and Facilitators to Treatment Seeking for Infertility Among Women in the United States

2.1 Introduction

Infertility, defined as disease of the reproductive system that prevents the conception of a child or the ability to carry a pregnancy to delivery, is a global public health issue with known negative psychological, financial, and social consequences that can have a devastating impact on the wellbeing of a woman (World Health Organization, 2019; Lemoine & Ravisky, 2013; American Society for Reproductive Medicine, 2019). Among women who experience challenges with family building due to infertility, it is well established they commonly experience high rates of depression, anxiety, distress, loss of control, sexual dysfunction, and lower quality of life (Williams, 1997; Cousineau & Domar, 2007; Kucur Suna et al., 2016; Ghraib & Khait, 2017; Jung & Kim, 2017; Imran & Ramzan, 2017; Joelsson et al., 2017). Financial strains stem from decreased productivity at work due to psycho-emotional burdens (Hanna & Gough, 2019) along with losses of economic opportunities due to divorce or sociocultural norms and attitudes (Dyer & Patel, 2012). Further, women experiencing infertility have also been known to experience lower marital satisfaction and social isolation due to stigmatization of the disease process (Dyer & Patel, 2012).
Recent reports from the National Survey of Family Growth (2018) in the United States showed that women ages 15-44 frequently experience infertility, with a prevalence rate that is upwards of 16.2% among all women regardless of marital status. However, previous epidemiological studies that examine prevalence and incidence of infertility diagnosis and treatment utilization in the United States have shown that between 12% (Kessler et al., 2013) to 50% (Chandra et al., 2013) of women who meet the criteria for infertility actually seek treatment. Therefore, the prevalence of infertility can be much higher than projected. Both the Centers for Disease Control (CDC) and the World Health Organization (WHO) have proposed extensive plans to decrease the prevalence and incidence of infertility that mainly stress improved access to expeditious diagnosis and treatment for this disease for all women and families struggling to conceive as a result of infertility (World Health Organization, 2019; CDC 2019, Warner et al., 2015). However, disparities in treatment seeking and utilization, specifically in the United States, have seemingly only benefitted older women of White Non-Hispanic ethnicities with high income and high levels of education (Dyer & Patel, 2012; CDC 2019; Warner et al., 2015; Shapiro et al., 2017; Quinn & Fujimoto, 2016). Although income has often been posited as the most influential factor affecting treatment seeking, 16 states currently mandate some form of insurance coverage for infertility and many of these disparities continue to exist (Mattocks et al., 2015; Buckles, 2013; Schmidt, 2007). It is unclear what etiological
and other risk factors, beyond these sociodemographic variables, contribute to the low levels of treatment seeking in diverse samples.

Considering there are multiple psychological, financial, and social consequences to infertility, there is a need to identify a comprehensive understanding of the facilitators and barriers influencing women as they consider accessing infertility treatment. Understanding these factors could help in shaping public policy or developing targeted clinical interventions for early identification of infertile women to promote healthy experiences with fertility treatment use to help with family building. Previous systematic reviews of treatment seeking decisions are quite limited and have focused on factors related to treatment discontinuation (Dyer & Patel, 2012). Therefore, the purpose of this systematic review is to provide a comprehensive review of literature that examined facilitators and barriers to infertility treatment seeking among women who experience infertility in the United States.

2.1.1 Theoretical Framework

Chrisman’s (1977) Health Seeking Process Model was used to organize and guide this systematic review. This model was selected over others because of its focus on sociocultural and contextual factors that have often been overlooked in the infertility treatment seeking literature. This model incorporates five conceptual components: symptom definition, illness-related shifts in role behavior, lay consultation and referral, treatment actions, and adherence. Since the review sought to understand the variety of
facilitators and barriers leading to initial treatment seeking, the final phase of adherence was not explored. The domains represent the sequential process an individual experiences to engage in treatment seeking. The model posits that before a person seeks treatment, they must be aware of and hold certain beliefs about their symptoms, which may have bearing on their role in society. Upon reconciling the biological understanding and potential psychosocial effects of the disease, the person will often explore varying degrees of consultation and treatment options. Each step along this chain holds opportunities for barriers or facilitators to influence the trajectory of the person’s health-seeking behavior. The following discussion further defines the four domains included in this review and details the importance of including them for synthesizing results of studies that are relevant to treatment seeking.

Symptom definition refers to the person’s perception of an illness or condition that effects whether a person seeks treatment or not (Chrisman, 1977). Symptom definition seeks to define how the person may perceive the illness as a danger or disability. Dangers include direct implications of having the disease, while disability explores the direct impact that inhibits life functioning. Symptom definition can be measured in the context of infertile women by measuring perceptions, knowledge, or awareness of the infertility disease state and how that may or may not correlate with increased treatment seeking.
Chrisman describes role-illness change as a potent mediating factor leading to treatment seeking because of the direct impact on the role a woman has in her social settings. If a woman perceives that she cannot fulfill her role, she could be further motivated to seek care. For example, a wife’s role is changed when she conceptually becomes an “infertile wife,” prompting treatment seeking (Chrisman, 1977). This area is measured by looking at culturally important roles that are affected by infertility such as personal desires to have children, partner mandates, or level of paternalistic society mandates.

Lay consultation and referral refer to the individual who begins contacting members of their social network to help with their illness or condition (Chrisman, 1977). This phase suggests that the patient seeking care will ultimately disclose their desires for treatment to individuals who they deem as valuable resources. Chrisman characterizes this approach as either parochial or cosmopolitan. The parochial approach is categorized as more traditional where a woman tries to connect with inner circles first. Conversely, the cosmopolitan person would be open to broader avenues of referral. This area of the model is measured by looking at influences by and interactions with social support systems with regard to seeking infertility care.

Finally, treatment actions examine broadly what treatment a woman undergoes and how the directive originated, be it internally or externally. There are four treatment types: (1) activity alterations, (2) application or ingestion of substances, (3) verbal or
ritual behaviors, and (4) physical interventions of the body. The treatment types can be classified under five treatment sources: (1) formal health professions, (2) licensed health practitioners, (3) alternative practitioners, (4) lay consults, and (5) self.

2.2 Methods

2.2.1 Search Strategy

This review followed a registered protocol (Currently awaiting final registration number for PROSPERO) and PRISMA guidelines. Studies were included if they reported factors specifically influencing treatment seeking patterns of women for infertility as defined above. The search was conducted in January 2019 in four databases. A library scientist and co-author of this paper searched Pubmed, CINAHL, PsychInfo, and Scopus, as seen in Figure 1. Citations and the systematic review were both managed in Covidence (Innovation VH, 2017). To maximize the retrieval of potentially relevant articles and to address issues of non-uniformity of defining treatment seeking, we utilized a combination of free texts, index terms, and truncated terms. The following terms and concepts were used: infertility [or] subfertility; woman [or] women [or] female; patient acceptance of health care [or] help-seeking [or] health seeking behaviors [or] treatment seeking. The search terms were purposely used to include variations of terms that were synonymous with treatment seeking.

For each reference in the final output, two authors double screened the title and abstract for inclusion. Covidence reported studies that had discrepancies in screening,
and those differences were discussed and a final decision was made. Two authors reviewed the full text of included studies and discussed and reconciled discrepancies. Citations identified from reference checks were discussed and included if they met eligibility criteria. A final review of all included studies included discussion from all authors.

2.2.2 Inclusion Criteria

The inclusion criteria are as follows:

1. Studies must have explicitly discussed the relationship of variables that influenced treatment seeking among women in the United States. As views of family building methods and degree of pro-natalism/anti-natalism are diverse among cultures/nations, it was appropriate to include studies done in the United States only. Treatment seeking was defined as the process in which women sought information or care for concerns related to their inability to conceive or reach live birth.

2. Studies must have been original research studies published from January 2000 to February 2020. The year limits were chosen to obtain a timely understanding of recent trends in treatment seeking as technology within reproductive endocrinology has modernized in recent years.

3. Studies must have been written in English.
To ensure the aims of the review were adequately met, discussion of each article during the full-text screening occurred between at least two authors. Studies commonly excluded were:

1. Those that merely discussed the socio-demographics of a treatment-seeking population and not any causal inference;
2. Studies that analyzed the outcome from male and females but did not present sub-analysis data of the female sample’s results.

The screening process and reasons for exclusion can be found in Figure 1.

### 2.2.3 Data Extraction & Synthesis:

Using Covidence as an extraction tool, one author extracted data from all of the studies. Extracted data included: study location, study design, sample characteristics, measures, and outcome on treatment seeking. Quality assessment was conducted using the critical appraisal tool from the Joana Briggs Institute (2014). Two reviewers critically assessed the studies independently from each other, answering “Yes,” “No,” “Unclear,” or “Not applicable” to eight questions (for cross-sectional studies) or ten questions (for qualitative research studies) about methodological main concerns. After these two independent reviews, any discrepancies were discussed. Each study was displayed with its total points, and the number of “Yes” responses was added up for each study. We considered every study that met the inclusion criteria, independent of their quality. Quality appraisal scores are in Table 1. The articles were synthesized and reported as
either a barrier or facilitator to treatment seeking within the four domains of Chrisman’s Health. For quantitative articles, significant findings were abstracted and discussed in the results sections. For qualitative articles, the major themes reported were included in our analysis.
### Table 1. Sample of Systematic Review (N=22)

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Data Type/ Study Design</th>
<th>Theoretical Model</th>
<th>Sample</th>
<th>Aim</th>
<th>Facilitator to Treatment Seeking</th>
<th>Barrier to Treatment Seeking</th>
<th>Quality Appraisal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aghajanova et al., 2017</td>
<td>Quantitative Cross-Sectional</td>
<td>n/a</td>
<td>220 female resident physicians total; 18 responded as experiencing infertility</td>
<td>Understand the prevalence, experience, and utilization of infertility services among Ob/Gyn residents across the United States</td>
<td>1. Time Constraints (40%) 2. Did not perceive a need for treatment (20%) 3. Affordability (20%) 4. Low Support from Supervisors (63%)</td>
<td>5/8</td>
<td></td>
</tr>
<tr>
<td>Bell, 2014</td>
<td>Qualitative Case Study</td>
<td>n/a</td>
<td>58 women experiencing infertility mix of high and low SES</td>
<td>Health information influences an individual’s health outcomes</td>
<td>1. High Social Support 2. Advanced Health Literacy/Quality of Information. 3. Enhanced Agency of Treatment Decisions</td>
<td>1. Low Social Support 2. Advanced Health Literacy/Quality of Information.</td>
<td>9/10</td>
</tr>
<tr>
<td>Bell 2016</td>
<td>Qualitative Descriptive Study</td>
<td>n/a</td>
<td>65 women experiencing infertility; 41 low SES, 17 high SES; 24 same sex</td>
<td>Understanding of stratified medicalization along various dimensions of inequality: gender, class, and sexuality.</td>
<td>1. Positive Beliefs in treatment Efficacy; 2. Advanced Health Literacy; 3. Positive Patient-Provider Interactions</td>
<td>1. Internalized Stigma due to Diagnosis 2. Same-sex infertility 3. Access Limited by Professional Obligations 4. Internalized Exclusion from Access</td>
<td>9/10</td>
</tr>
<tr>
<td>Study</td>
<td>Type</td>
<td>Details</td>
<td>Participants</td>
<td>Motivations for Medicalized Infertility</td>
<td>Outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>-----------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>----------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Crawford 2017</td>
<td>Quantitative Cross-Sectional (BRFSS)</td>
<td>n/a</td>
<td>1272 women who experienced infertility or difficulty staying pregnant</td>
<td>1. Primary infertility with no conception</td>
<td>1. Difficulty staying pregnant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duthie 2017</td>
<td>Quantitative/ Cross-Sectional</td>
<td>n/a</td>
<td>59 women who scheduled a 1st infertility consult</td>
<td>1. High Desire for Parenthood one way or another. 2. Alignment with Partner. 3. Desire for parenthood in short timeline</td>
<td>8/8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>Research Questions</td>
<td>Relevant Findings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>------</td>
<td>--------------</td>
<td>-------------</td>
<td>-------------------</td>
<td>-------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goossen</td>
<td>2019</td>
<td>Quantitative/Cross-Sectional</td>
<td>1004 Female veterans</td>
<td>Experiences of female veterans with infertility</td>
<td>1. Negative Beliefs of Treatment Efficacy for both White and minority veterans. 2. Non-specific social factors for White. 3. Uncertainty for White veterans. 4. Unwanted pregnancy and lack of awareness for racial minorities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greil</td>
<td>2010</td>
<td>Quantitative Cross-Sectional (NSFB)</td>
<td>2,183 women ever experiencing an episode of infertility</td>
<td>Assess the influence of various aspects of religiosity on infertility help-seeking</td>
<td>1. High Importance of Motherhood. 2. Primary Infertility. 3. Intentions to Treat Infertility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greil</td>
<td>2011</td>
<td>Quantitative Cross-Sectional</td>
<td>1027 women who reported infertility in last 10 years (NSFB)</td>
<td>Compare experiences of infertility type on fertility specific distress and help-seeking</td>
<td>1. Primary infertility with no conception</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Type</td>
<td>Design</td>
<td>Sample Size</td>
<td>Methods</td>
<td>Findings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>-------------------------------</td>
<td>-------------------------</td>
<td>-------------</td>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greil 2013</td>
<td>Quantitative</td>
<td>Cross-Sectional</td>
<td>1188</td>
<td>Theories of Health Services Utilization</td>
<td>Identify the role of social cues, enabling conditions, perceived need, and social location on health service utilization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jacob et al, 2007</td>
<td>Quantitative</td>
<td>Cross-Sectional</td>
<td>248</td>
<td>Women who reported infertility episode within past 10 years (NSFB)</td>
<td>1. High Social Support and Influence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mattocks 2011</td>
<td>Qualitative</td>
<td>Descriptive</td>
<td>25</td>
<td>Women veteran’s experiences and preferences with reproductive health care services</td>
<td>1. Perceptions of limited availability to infertility care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Type</td>
<td>N/A</td>
<td>Sample Size</td>
<td>Summary Description</td>
<td>Findings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>-------------------------------</td>
<td>-----</td>
<td>-------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>McCarthy 2011</td>
<td>Quantitative Cross-Sectional</td>
<td>n/a</td>
<td>142 women</td>
<td>Examine differences in psychological and social dimensions among women with reported fertility problems and who elected to seek or not seek medical treatment</td>
<td>1. Lower Self-esteem; 2. Low Life Satisfaction; 3. Low Importance of Parenthood</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missmer 2011</td>
<td>Quantitative Cross-Sectional</td>
<td>n/a</td>
<td>743 women</td>
<td>Identify cultural differences in accessing infertility care</td>
<td>1. Professional Obligations; 8/8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nachtigall 2009</td>
<td>Qualitative/Descriptive Study</td>
<td>n/a</td>
<td>105 infertile female immigrants</td>
<td>Experiences of low income latino population seeking infertility services</td>
<td>1. Negative Patient-Provider Interactions due to Language and Cultural Barriers. 8/10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Design Type</td>
<td>Participants</td>
<td>Research Focus</td>
<td>Key Findings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td>------------------------------</td>
<td>--------------</td>
<td>----------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Slauson-Blevins 2013 | Quantitative Cross-Sectional (NSFB) | 1352 women who met criteria for infertility | Understanding type of health-seeking among women with infertility issues | 1. Positive Beliefs in treatment Efficacy (Symptom salience).  
2. Positive attitudes towards Medical Science.  
4. Encouragement from partner, family/friends, and those who also sought treatment |
| White 2006   | Quantitative Cross-Sectional | 196 women ever experiencing infertility | Examining cognitive appraisal of infertility and medical helpseeking | 1. Perceiving a fertility problem  
2. Perceived good health |
2.3 Results

2.3.1 Sample Characteristics

A total of 20 studies met inclusion/exclusion criteria and are included in this review (see PRISMA Flowchart in Figure 1).

Figure 1: PRISMA Flow Diagram
The sample included six qualitative studies and 14 quantitative studies. All of the quantitative studies were observational studies examining cross-sectional data sources. The most common data sources were from the National Survey of Fertility Barriers being (n=6). Quality Scores ranged from 62.5% to 100% and utilized two types of Joanna Briggs Quality Appraisal Checklists, the cross-sectional (n=14) and qualitative studies (n=6) appraisal tools (Joanna Briggs Institute, 2017; Lockwood et al., 2015). Quality appraisal scores for individual studies are listed in Appendix 1. Samples ranged from 24 to 2,183 women. Of the 15 studies that reported some aspect of their samples’ race/ethnicity, three (Greil & McQuillan, 2004; Johnson & Johnson, 2009; Slauson-Blevins et al., 2013) studies reported the samples as either “Non-White or White.” The majority racial ethnic category was White non-Hispanic women except for two studies that purposively sampled for either African American (Ceballo et al., 2015) or Latina women (Nachtigall et al., 2009). The majority of the samples within these two studies were low-income women. 17 studies examined factors that influenced women to seek treatment among cohorts who self-reported meeting the criteria for infertility. The three studies that did not specifically explore factors that influence treatment seeking among women experiencing infertility were studies that aimed to provide a broader scope of health care utilization among women, and subsequent analysis revealed facilitators or barriers
related to infertility treatment seeking (Aghajanova et al., 2017; Goossen et al., 2019; Mattocks et al., 2011). Finally, five (Johnson & Johnson, 2009; Slauson-Blevins et al., 2013; Ceballo et al., 2015; White et al., 2006; Greil et al., 2013) studies utilized a guiding theoretical framework for their studies using five unique frameworks to understand treatment seeking among women experiencing fertility.

2.3.2 Symptom Definition

According to Chrisman’s model (1977), symptom definition seeks to define how the person may perceive the illness as a danger or disability and how this perception affects treatment behaviors. Within this review, studies reported that facilitators of treatment seeking were heavily influenced by infertility type. Women who were not able to conceive, especially the first time (commonly referred to as primary infertility) (Greil, Shreffler, et al., 2013; Greil, Johnson, et al., 2013), were more likely to seek treatment than women who had difficulty maintaining a pregnancy (Crawford et al., 2017). Finally, perceiving one’s self as having fertility issues (White et al., 2006; Jacob et al., 2007) and experiencing higher levels of fertility distress (Jacob et al., 2007) also caused higher uptake of treatment seeking behaviors. The studies also showed that barriers to treatment seeking included negative self-views of internalized stigma (Slauson-Blevins et al., 2013; Bell, 2016; Missmer et al., 2011), especially in the context of a same sex relationship (Bell, 2016) or low self-esteem (McCarthy & Chiu, 2011). One study noted
that perceptions of low risk of ever being diagnosed with infertility commonly prevented women from seeking care (Aghajanova et al., 2017).

2.3.3 Role-Illness Change

Chrisman (1977) describes role-illness change as a potent mediating factor leading to treatment seeking because of the direct impact on the role a woman has in her social settings. The reviewed studies showed the most prominent facilitators to treatment seeking were high life satisfaction (Johnson & Johnson, 2009; McCarthy & Chiu, 2011) and high desire for parenthood (Johnson & Johnson, 2009; Greil, Shreffler, et al., 2013; McCarthy & Chiu, 2011; Duthie et al., 2017). This desire was especially salient when this desire for parenthood aligned with partners’ responses (Johnson & Johnson, 2009; Slauson-Blevins, McQuillan & Greil, 2013; Greil, Shreffler, et al., 2013; Duthie et al., 2017). Further, some women were more compelled to seek treatment when they feared disappointing their partners (Missmer et al., 2011). However, a sample of only Black women revealed that beliefs in the social construction of motherhood was neither a barrier nor facilitator (Ceballo et al., 2015).

2.3.4 Lay Consultation & Referral

Lay consultation and referral refer to the individual who begins contacting members of their social network to help with their illness or condition, which may include close friends and relatives or clinical providers (Chrisman, 1977). The
interactions within these social and clinical settings could inhibit or influence treatment seeking for infertility. The study revealed that facilitators to treatment seeking included women with high social capital of individuals or groups who supported fertility treatment; which included religious leaders and fertility support groups (Greil & McQuillan, 2004; Slauson-Blevins et al., 2013; Greil, Shreffler, et al., 2013; Collins & Chan, 2017). Additional facilitators included women who had advanced health literacy/knowledge of infertility disease and treatment (Bell, 2016) typically related to access to high quality/accurate information (Greil & McQuillan, 2004; Slauson-Blevins et al., 2013; Bell, 2014; Bell, 2017). Other facilitators included having positive patient-provider interactions (Mattocks et al., 2015; Ceballo et al., 2013) when introducing initial fertility concerns.

There were numerous barriers within the domain of Lay Consultation & Referral across several studies. Barriers included access to available treatment being limited by professional obligations (Aghajanova et al., 2017; Nachtigall et al., 2009; Bell, 2016) especially among African American and Hispanic women (Missmer, 2011). Women who perceived the affordability of treatment as not being realistic (Aghajanova et al., 2017) and those who perceived they were inherently excluded from receiving treatment (i.e. thinking fertility treatment was for wealthy people) (Mattocks et al., 2011; Bell, 2016; Missmer, 2011) were also least likely to seek care. Socially, women with low social
support (Nachtigall et al., 2009; Missmer, 2011) or with support that suggested non-treatment options (Collins & Chan, 2017) were less likely to seek care. However, barriers to receiving appointments based on perceived bias of race/ethnicity and income were less likely to seek care, affecting primarily African American and Hispanic groups (p<0.0001) (Missmer, 2011; Bell, 2014). Finally, women who had to self-refer were least likely to seek care. African American women were five times more likely to be self-referred (p=.006) than Non-Hispanic White women (Missmer, 2011). Finally lack of access to high quality educational materials were associated with limited engagement in clinical or social consultation (Greil & McQuillan, 2004; Bell, 2014).

2.3.5 Treatment Actions

Finally, treatment actions examine broadly what treatment a woman does and from where these directives originated, either personally or from outside sources (Chrisman, 1977). Among this sample, women were more likely to support and engage in clinical interventions when they had positive beliefs of treatment efficacy (Slauson-Blevins et al., 2013; Bell, 2016; Bell, 2017) or felt they had enhanced agency over treatment decision (Bell, 2014). Barriers to treatment action were due to negative beliefs of treatment efficacy (Ceballo et al., 2015; Goossen et al., 2019; Missmer, 2011).
2.4 Discussion

Infertility is a devastating disease with numerous consequences to the psychological, social, and emotional health of women and families (Williams, 1997; Cousineau & Domar, 2007; Imran & Ramzan, 2017; Joelsson et al., 2017; Chrisman, 1977). Only 50% of women who experience infertility will seek treatment (Chandra et al., 2013). Previous literature had failed to identify factors beyond sociodemographic factors that contribute to low levels of treatment seeking. A total of 20 articles that examined facilitators and barriers that influenced treatment seeking among women who experienced infertility in the United States were included in this systematic review and were synthesized using Chrisman’s Health-Seeking Model. Findings suggest there are multi-factorial facilitators and barriers that influence treatment seeking. Although studies did not have a uniform method of collecting study variables with regard to mediating factors and treatment seeking outcomes, the most common variables associated with enhanced treatment seeking were: high desire for parenthood especially when their partners also agreed, high social support encouraging treatment, and advanced health literacy. The more common barriers included: internalized stigma, having access limited by professional careers, and low or no social support supporting treatment seeking, and negative perceptions of the clinical environment. Overall, many
of the facilitators and barriers found were a dynamic blend of perceptions of the biological, clinical, and social implications of disease and treatment access.

Many of the barriers and facilitators found were consistent with other studies that examined these influences on treatment seeking in other disease processes. Within our review, we found that health-related stigma negatively influenced how women viewed the disease of infertility, identities associated with infertility, and perceptions regarding who can utilize treatment. In a review of the theoretical basis of the complexities of stigma (Pescosolido & Martin, 2015), authors noted health-related stigma is well-established as a factor affecting medical help-seeking and other treatment decisions. This theory has been highly explored in groups of women who experience other stigmatized disease processes. Positive perceptions regarding the normalcy of symptoms and options for treatment were known facilitators for women with urinary incontinence to seek care (Koch, 2006). Whereas, self-shame and low self-esteem were found as prominent barriers to treatment seeking in review of women suffering from vulvodynia (Shallcross et al., 2018).

Further, this health-related stigma seemed to also negatively influence women’s perceptions of and experiences with the clinical environment. Women, especially those from low socioeconomic and racial/ethnic minority groups (Bell, 2016; Bell, 2014; Bell,
2017), held deeply rooted beliefs that infertility services were prioritized for more affluent groups. This was particularly true in one study where women perceived their lack of referral to be a result of clinician decisions being affected by race and income (Missmer, 2011). These findings suggest that women often perceive that their income and racial standing are salient barriers to care. It would be worthy to explore whether these beliefs remain in states where insurance mandates for infertility services are enacted. Further, implicit bias has been a well-established factor that leads to differences in treatment in many diseases (Carter et al., 2017; Cebert et al., 2019) especially among minority populations across a myriad of diseases including women’s health. The incidence of implicit bias within reproductive endocrinology should be explored. Nevertheless, the infertility health-related stigma shown in our review, suggests a need for interventional work that aims to enhance understanding of disease risk, symptoms, and availability of treatment options.

Many of the studies included in this review noted the importance of partner agreement, partner encouragement, and the role of social networks to provide support in decisions to seek treatment. This finding is consistent with previous studies that highlight treatment seeking processes within women’s health are interrelated and decided upon jointly with the male partners (Fasse et al., 2017; Kuo et al., 2019; Osamor & Grady, 2018). However, most of the partners discussed in the research on infertility
treatment seeking were from heterosexual partnerships. The current review included only one study that specifically mentioned sampling same-sex women (Bell, 2017). Partner involvement in infertility treatment seeking among diverse sexual orientations would be worthy to explore as their treatment seeking patterns may reveal additional barriers to infertility treatment, possibly mirroring the marginalized experiences they face with other reproductive health issues (Wingo & Ingraham, 2018). Further, with regard to social support, the positive or negative nature of social support has been well reviewed and shown to enhance treatment seeking among women with experiences such as eating disorders* or mental health disorders (Magaard et al., 2017; Ketcheson, 2017). However, it was noteworthy that in this review, social support differed among ethnic groups and this concept should be explored more in diverse samples as coping with infertility is known to differ among cultures (Li & Liu, 2014).

2.4.1 Strengths and Limitations

To the best of our knowledge, this is the first review to provide a comprehensive assessment of etiological and risk factors contributing to treatment seeking for infertility among women in the United States. With the strict inclusion and exclusion criteria, all 20 studies included were highly reflective of the main aim of this review to understand the facilitators and barriers of women who seek treatment for infertility. However, the authors do consider that this may not be a comprehensive list of articles exploring
treatment seeking for infertility due to a lack of consistent terminology used for
treatment seeking. However, one of the authors is a librarian scientist who ensured a
comprehensive search of the database. Also, the analysis utilized a well-established
theoretical framework commonly used in bio-behavioral research. The study designs
were mainly observational studies utilizing cohort, case-control, and cross-sectional
designs with nationally represented samples. Therefore, many of these studies could not
establish causal inference. Further, many studies did not mention the use of a guiding
theoretical model to their treatment seeking research. This potentially influenced the
variations of measures collected across the studies.

2.4.2 Implications

To date, studies of facilitators and barriers to women seeking treatment are
limited in scope and number, and provide very little information on current facilitators
and barriers to infertility treatment seeking. There were several implications for
research, practice, and policy. Addressing gaps in research that focus on facilitators and
barriers to infertility treatment can be a multidisciplinary venture through many fields.
Scientists interested in factors that influence medical decision making should consider
using guiding theoretical models to promote comprehensive and consistent data
collection. Also, since infertility treatment access could be influenced by local policy,
intentionally recruiting samples from states with infertility insurance mandates and
explicating the findings with regard to geographic differences could expand previous literature that examined differences in treatment use in insurance mandated states (Ketcheson, 2017; Li & Liu, 2014). Only one study in this review (Collins & Chan, 2017) purposefully recruited in a state with mandates for private insurance to cover infertility. Dually, conducting these studies in the clinical environment could provide a more comprehensive understanding of the health of these participants, especially if comorbidities or other biological factors influence care. More research is also needed in this area to understand variations in treatment-seeking among racial and ethnic groups. Information regarding multicultural experiences of treatment seeking for infertility would provide a foundation for developing targeted interventions addressing the unique needs of women in regards to accessing services. Further inquiry regarding the clinical encounter should be explored as the lack of providers, discomfort with physicians, and guidance to delay treatment by a physician were all found to be barriers to health promoting activities of treatment seeking.

Clinically, the findings of this study suggest that reproductive health practitioners should provide evidenced-based information on infertility and the diversity of treatment options available. Practitioners are also well-positioned to provide realistic expectations of treatment efficacy and availability. However, more research is needed to understand how implicit bias or some other factor within the clinical
environment may be preventing these teaching moments from occurring. Mental health professionals should also be included in treatment models to help reduce the psychological effects of diagnosis and improve perceptions of identity.

Finally, policy should continue to support primary and secondary prevention strategies to promote prompt and effective diagnoses and treatment for infertility. Since this review included studies surveying women from nationally representative samples, there should be exploration of how federal mandates could improve treatment access and utilization. Lawmakers should also consider enhancing infertility education in school-based sexual education programs to improve awareness.

2.4.3 Conclusions

Our findings are important for public health because they provide a multi-dimensional understanding of disparities in treatment utilization within the United States. Many of the factors that influence treatment seeking are diverse, and more targeted interventions may need to be developed to decrease the devastating short- and long-term effects of infertility. This review highlighted several areas where researchers, practitioners, and policymakers should use more holistic approaches to improve utilization of infertility treatment for many Americans.
3. Psychobiological, Clinical, and Social Factors Associated with the Initiation and Completion of the Recommended Treatment Plan for Infertility among Black Women

3.1 Introduction

Infertility is defined as the inability to become or remain pregnant after 12 months of consistent sexual intercourse (ASRM, 2019). In the United States, 13.1% of all women ages 15 to 44 years old report experiencing infertility (CDC, 2019). Despite these estimates, it is well established that the actual prevalence of infertility is underreported and up to 50% of women with symptomology consistent with infertility will ultimately seek evaluation (Chandra et al., 2013). Additional reports have shown that 7.4 million women in childbearing ages 15-44 have used some type of infertility services for family building, accounting for 12% of the total female population (CDC, 2019). Among those who seek treatment, rates of not initiating treatment after diagnosis can range from 13% (Eisenberg et al., 2010) to 36% (Crawford et al., 2016). Although limited, the literature suggests that reasons for treatment initiation or non-initiation can be multi-dimensional. Reasons for not initiating treatment for infertility are associated with positive depression screen, emotional distress, personal life events, and beliefs of treatment futility (Crawford et al., 2016; Eisenberg et al., 2010). However, women who initiated treatment plans were found to have positive attitudes towards patient-centered care (Pedro et al., 2013).
The literature that discusses decisions from initial reproductive endocrinology evaluation to treatment onset in the U.S. often highlight the experiences of mainly affluent, highly educated, and older Non-Hispanic White women. This inequity in scientific inquiry is concerning considering that several studies have shown that Black women in the U.S. have twice the prevalence of infertility (14%) than non-Hispanic White women (7%) yet are twice as less likely to seek initial evaluation for infertility (Chin et al., 2015; Dieke et al., 2017; Quinn & Fujimoto, 2016; Shapiro et al., 2017; Chandra et al., 2013). Disparities in infertility treatment use among Black women are crucial to promote health and wellness in this population. Childbearing is a culturally central component of Black families (Hill, 2001), and Black women with infertility experience notable alterations to their self and gender identity, high levels of isolation, silence, and negative medical experiences related to their fertility status (Ceballo et al., 2015). Despite these negative experiences among Black women, the literature fails to highlight reasons for lower uptake of infertility treatment beyond sociodemographic factors.

### 3.2 Theoretical Framework

A theoretical framework adapted from literature on treatment seeking and Chrisman’s Health Seeking Process Model guided this study (Chrisman, 1977). The Chrisman’s Health Seeking Process model explores the relationship of sociocultural
imperatives of everyday life affecting patterns of health beliefs and practices through its five conceptual domains: symptom definition, illness-related shifts in role behavior, lay consultation and referral, treatment actions, and treatment completion. These domains integrate the biological, clinical, psychological, social, and cultural factors that form the complex environments in which individuals pursue evaluations and the degree to which they act and adhere to treatment recommendations.
Figure 2: Health Seeking Process of Black Women Who Undergo Evaluation for Infertility and Decide to Initiate Infertility Treatment

Figure 2 posits that there are multidimensional factors and perceptions that are in relationship with one another and are continuous throughout the process of health seeking from the onset of symptoms, to an evaluation by a reproductive endocrinologist, and subsequent treatment actions taken to initiate and complete the recommended
treatment plan. The stage of initial evaluation is starred because not every woman will seek primary evaluation from general practitioners prior to meeting with reproductive endocrinology. The culmination of these psychobiological, clinical, and sociocultural dimensions merge together to predict the main outcome, initiation of the recommended treatment plan, and may also influence treatment completion.

3.3 Specific Aims

Previous studies have often described the demographic characteristics of women in the U.S. who seek treatment and their treatment outcomes. However, that information does not include key factors that could influence treatment initiation such as past medical/gynecological history, infertility diagnoses, treatment plan recommendations, and insurance. Similarly, the literature fails to describe the characteristics of women who have sought evaluation and decided to initiate treatment. Further, factors related to treatment completion are not well-documented. Therefore, the aims of this study were to:

Aim 1. Describe the psychobiological, clinical, and social characteristics of Black women who seek evaluation for infertility by a reproductive endocrinology specialist.
**Aim 2.** Identify psychobiological, clinical, and social factors related to the initiation of a recommended treatment plan for infertility among Black women who undergo a reproductive endocrinology evaluation.

**Aim 3.** Explore psychobiological, clinical, and social factors associated with completion of infertility treatment among the Black women who initiate the recommended treatment plan.

### 3.4 Methods

#### 3.4.1 Design

The study utilized a retrospective cohort design that addressed the study aims among Black women (ages 15-44) who sought treatment for infertility and were observed over a 3-month period. Although previous studies have examined treatment initiation within four months (Crawford et al., 2017), the three-month time period for this study was chosen based on this particular clinic’s guidelines of when they would consider patients to be initiators or non-initiators. Psychobiological, clinical, and social variables developed *a priori* were abstracted from individual electronic health records accessed from a system managed by a private infertility clinic.

Institutional review board approval for this study was obtained at Duke University Health System with permission from the private fertility clinic’s research team. The fertility clinic is a privately owned entity with no academic affiliation;
therefore, study procedures and conduct were reviewed and approved by the researcher’s primary institution.

3.4.2 Setting

Participants were recruited from a large infertility center in a metropolitan area in the northeastern region of the U.S. The location of this clinic was selected due to being situated in a state with active insurance mandates to cover infertility treatment services. In addition to its main facility, there are nearly a dozen other satellite offices in the same state. The private infertility center includes a large group of physicians, advanced practice providers, nurses, and technicians, and a full-service on-site hematology, embryology, and andrology lab. The clinic offers broad and comprehensive services such as treatment for male and female factor infertility, treatment for single and partnered men and women, third-party services (gestational carriers, donor eggs), cryopreservation, pre-genetic testing and screenings, and mental health services.

3.4.3 Sample and Subsample

Electronic health records were selected using population-based sampling to extract all eligible charts from the private infertility clinic. Inclusion criteria were women who self-identified as African-American/Black, between the ages of 18 and 44 years old, who presented for an initial infertility evaluation with a male partner between January 2015 and September 2019. Although male partners did not need to be present at the
initial evaluation, diagnostic results would need to specify women were seeking

treatment with a male partner. Because only 16 states include infertility treatment as
mandated in private health insurance, women who were seen at any of the infertility
center’s offices that were in the same state as its main facility were included. Women
excluded from the study were single or unpartnered women, women who sought
fertility cryopreservation, or women seeking conception services who were in a same-
sex partnership. We excluded these groups because they may experience additional or
different factors that influence treatment initiation. Finally, because the infertility center
has satellite offices in other states than its main facility that lack mandated insurance
coverage, we excluded women seen at those centers.

This process yielded a sample of Black women who sought and underwent an
evaluation for infertility by a reproductive endocrinology specialist (Aims 1 and 2,
infertility sample). Among those, women who subsequently decided to initiate
treatment for infertility were evaluated for treatment completion (Aim 3, treatment
initiation subsample).

3.4.4 Procedures

A retrospective chart review of Black women evaluated for infertility at the clinic
was conducted. We queried all visits by Black women who had a reproductive
endocrinology visit at the infertility clinic between January 2015 to September 2019
(N=8200). Following the identification of 3,326 individual patient records during this timeframe, SAS™ software (Cary, NC) was used to assign each a unique random identification (random ID) using a random number generator. The random ID assigned to each patient was sorted in ascending order. Charts were reviewed one by one in sequential order by random ID and each sequential visit record was screened for study eligibility based on the inclusion and exclusion criteria. The first 391 patient records that met the eligibility criteria were included in the infertility sample (see Figure 3). A primary abstractor completed the manual abstraction of the study variables for all 391 patients. To assess whether each patient initiated infertility treatment, the cohort was followed for three months from the time of the first follow-up visit.

Figure 3: Process for Obtaining the Infertility Sample (N=391)
3.4.4.1 Quality Assurance

We randomly selected 7.5% of 391 charts (N=30 charts) to assess inter-rater reliability (Libby et al., 2011) of the data coding. A second reviewer re-abstracted the predefined set of study variables for the 30 patients. We set our quality threshold for reliability as a kappa coefficient of 0.70 per variable.

3.4.5 Measures

3.4.5.1 Sample and Subsample Characteristics.

Patient characteristics of the infertility sample and those who ultimately initiated treatment included the number of months the women experienced infertility prior to seeking treatment and the year women completed their follow-up visit. Additional characteristics included past, current, or lifetime medical and gynecological diagnoses, results of genetic screening, baseline imaging, baseline fertility laboratory testing, and final infertility factor diagnoses.

3.4.5.2 Psychobiological, Clinical, and Social Factors.

The psychobiological (PB), clinical (CL), and social factors (SC) were identified a priori and selected from a literature review of studies that examined barriers and facilitators to treatment seeking and other literature that explored infertility treatment initiation. Psychobiological factors included age at evaluation and the proportions of
women who experienced infertility more than 12 months prior to seeking treatment and had body mass indexes greater than 25 kg/m². The past medical and past gynecological history diagnoses were collapsed in whether or not the patient had one or more of these diagnoses respectively. Clinical measures included whether women had one or more abnormal hormonal laboratory results, experienced primary versus secondary infertility, and final infertility diagnoses (e.g., Female-factor, Male-factor, Combined Male-Female factor, & Unexplained). Additionally, clinical factors included the specifics of the recommended treatment plan, which detailed the procedure (e.g. Intrauterine insemination, in vitro fertilization) or adjuvant medication (e.g. oral medication only, combination of oral and injection medications). Social measures were employment and qualifying insurance that covered infertility treatment. An example of qualified insurance would be shown in the chart as one that listed benefits for infertility. The full list of measures is noted in Table 2.

**Table 2: Psychobiological, Clinical, and Social Measures**

<table>
<thead>
<tr>
<th>Psychobiological Factors</th>
<th>Description/definition</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Numerical age of the patient seeking treatment</td>
<td>18-44</td>
</tr>
<tr>
<td>Months Experiencing Infertility</td>
<td>Time in months the patient waited to seek treatment for infertility</td>
<td>Continuous</td>
</tr>
<tr>
<td>Overweight/Obese</td>
<td>Body mass index (BMI) of greater than 25 kg/m²</td>
<td>0 = No, 1=Yes</td>
</tr>
<tr>
<td>Year</td>
<td>Year the patient completed their follow up visit where treatment plan was presented</td>
<td>2015, 2016, 2017, 2018, 2019</td>
</tr>
<tr>
<td>Total Comorbidities</td>
<td>Past medical history included one or more of the following diagnoses:</td>
<td>0=None, 1=1 or more</td>
</tr>
<tr>
<td>Hypertension Diagnosis</td>
<td>0=No, 1=Yes</td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>Anxiety Diagnosis</td>
<td>0=No, 1=Yes</td>
<td></td>
</tr>
<tr>
<td>Depression Diagnosis</td>
<td>0=No, 1=Yes</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>0=No, 1=Yes</td>
<td></td>
</tr>
<tr>
<td>Thyroid Abnormality</td>
<td>0=No, 1=Yes</td>
<td></td>
</tr>
<tr>
<td>Hypercholesterolemia</td>
<td>0=No, 1=Yes</td>
<td></td>
</tr>
</tbody>
</table>

**Gynecological History**

Past gynecological history included one or more of the following diagnoses:

<table>
<thead>
<tr>
<th></th>
<th>0= No, 1 =1 or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uterine fibroids</td>
<td></td>
</tr>
<tr>
<td>Endometriosis</td>
<td></td>
</tr>
<tr>
<td>Polycystic Ovarian Syndrome</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Pelvic inflammatory disease</td>
<td>0=No, 1=Yes</td>
</tr>
</tbody>
</table>

**Clinical Factors**

<table>
<thead>
<tr>
<th>Clinical Factor</th>
<th>Description/definition</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic Screen</td>
<td>Patient completed screen for genetic disorders</td>
<td>0=No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1= Yes, Normal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2=Yes, Abnormal</td>
</tr>
<tr>
<td>Abnormal Labs</td>
<td>At least one abnormal hormone related to ovulation:</td>
<td>0=None,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1=1 or more</td>
</tr>
<tr>
<td></td>
<td>Luteinizing Hormone</td>
<td>0=Normal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1=Abnormal</td>
</tr>
<tr>
<td></td>
<td>Progesterone</td>
<td>0=Normal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1=Abnormal</td>
</tr>
<tr>
<td></td>
<td>Prolactin</td>
<td>0=Normal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1= Abnormal</td>
</tr>
<tr>
<td>Anti-Mullerian Hormone (AMH)</td>
<td></td>
<td>0=Normal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1=Abnormal</td>
</tr>
<tr>
<td>Primary Infertility</td>
<td>Whether patient presented could not conceive AND achieve livebirth for the first time:</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Female Factor-Only Infertility</td>
<td>As a result of abnormal anatomy (shown by ultrasonography (US), hysterosalpingogram (HSG), or magnetic resonance imaging, abnormal hormones, or other reported underlying female-related issue.)</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Male Factor-Only Infertility</td>
<td>Presence of abnormal semen analysis or other reported underlying male-related issue.</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Combined Factor</td>
<td>Infertility results from a combination of female-related and male-related issues.</td>
<td>0=No, 1 = Yes</td>
</tr>
<tr>
<td>Unexplained Factor</td>
<td>An identifiable cause for infertility could not be determined</td>
<td>0=No, 1 = Yes</td>
</tr>
</tbody>
</table>

**Recommended Treatment Plan**

<table>
<thead>
<tr>
<th>Treatment Plan</th>
<th>Recommended treatment plan includes the use of only oral medications</th>
<th>0=No, 1 = Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral Medication Only</td>
<td>Recommended treatment plan includes the use of only intramuscular injections.</td>
<td>0=No, 1 = Yes</td>
</tr>
<tr>
<td>Intramuscular Injection</td>
<td>Recommended treatment plan includes both the use of oral and intramuscular medications.</td>
<td>0=No, 1 = Yes</td>
</tr>
<tr>
<td>Combination of Oral and Intramuscular Medications</td>
<td>Recommended treatment plan is for intrauterine insemination.</td>
<td>0=No, 1 = Yes</td>
</tr>
<tr>
<td>Intrauterine Insemination</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.4.5.3 Treatment Initiation Outcome.

The main outcome was initiation of the recommended treatment plan within three months. Patients were characterized as having initiated the recommended treatment if they received cycle-based (ovarian stimulation, intrauterine insemination, or in-vitro fertilization [IVF]), medical, or surgical treatment to optimize reproductive success (e.g., insulin-sensitizing medication, myomectomy for uterine fibroids, surgical treatment for endometriosis, etc.) within three months of their reproductive endocrinology evaluation (Eisenberg et al., 2010). Participants who did not undergo infertility testing or treatment after their initial evaluation during follow-up within three months were characterized as having not pursued treatment. Treatment initiation outcome was coded as 0=no and 1=yes based on these criteria.

3.4.5.4. Treatment Completion Outcome.

Treatment completion was defined as completion of all necessary tests, procedures, and protocols. Infertility treatment completion was evident when a final serum pregnancy lab was drawn two weeks following embryo transfer or insemination. Among the women who initiated treatment, treatment completion was coded as 0=no
and 1=yes based on these criteria. For those who completed treatment, data regarding whether the treatment result in a positive pregnancy test and livebirth were also determined.

3.4.6 Analysis Plan

Descriptive statistics were used to summarize the characteristics of the infertility sample and treatment initiation subsample as well as key study variables. Non-directional statistical tests were performed with the level of significance at 0.05 per test. The significance level was not adjusted for multiple outcomes or tests due to the exploratory nature of this study. Data were analyzed using SAS version 9.4™ software.

Descriptive statistics were used to detail the psychobiological, clinical, and social characteristics of those who underwent a reproductive endocrinology evaluation as well as the treatment initiation and completion outcomes (Aim 1, infertility sample, N=391). Bivariate and multivariable logistic regression models were used to examine the influence of these factors on initiation of infertility treatment within three months (Aim 2, N=391). The initial multivariable model included five psychobiological, eight clinical, and two social factors (see Table 2). A backward elimination variable selection method was then used to reduce the initial multivariable model to a final parsimonious model that included only those factors significant at the 0.05 level. Odds ratios (ORs) for bivariate analyses and adjusted odds ratios (aORs) for multivariable models and their
95% CIs were reported to estimate effect sizes and address clinical relevance. The same regression approach was also applied to explore which psychobiological, clinical, and social factors predicted treatment completion among the Black women who initiated treatment (Aim 3, treatment initiation subsample).

The study was initially powered to address the second aim. It was estimated that a sample size of 391 would provide at least 80% power for the initial multivariable regression model with 15 explanatory (PB, CL, SC) factors and treatment initiation as the outcome, assuming two-sided tests with significance set at 0.05 per test and medium effect sizes (aOR=2.47). The first aim was a descriptive analysis only. The third aim, an exploratory analysis of the subset of women who initiated treatment, focused on estimating effect sizes (aORs) and 95% CIs rather than statistical significance testing. Thus, the target sample size was 391 for the infertility sample.

3.5 Results

3.5.1 Quality Assurance

Inter-rater reliability for the coding data of 13 variables was conducted. Kappa coefficients of ≥ 0.70, indicative of strong agreement, was observed for all but one variable. Of the 13, there was 100% agreement on eight variables, including initiation and completion outcome variables (kappa = 1.00). Five variables had slight disagreement, namely year of follow-up visit (kappa = 0.83), history of depression...
diagnosis (kappa = 0.78), abnormal AMH (kappa = 0.74), in vitro fertilization as the treatment plan (kappa = 0.92). Insurance coding (kappa = 0.59) was the only variable that did not meet the 0.70 criterion. Discrepancies in the rater coding were discussed and additionally training was conducted to improve reliability.

### 3.5.2 Sample and Subsample Characteristics

Table 3 presents the characteristics for the infertility sample (N=391) and treatment initiation subsample (N=284). Among the 391 Black women who underwent a reproductive endocrinology evaluation, the median number of months from onset of infertility symptoms to initial evaluation was 24 months (range: 0 to 132 months). Hypertension was the most common comorbidity (7.2%) and over 26% had abnormal AMH. The majority of the women in this group (52.9%) had an abnormal HSG or US, while 44% of the women fertility diagnoses included male factor cause, whether alone or in conjunction with another contributing factor. Comprehensive testing revealed structurally associated abnormalities on the female exam, most notably fibroids (30.2%) and tubal disorders (36.3%). Among the 166 Black women who received a personal genetic screen, 41.6% had abnormal genetic screen results. Although we could not account for the entire year of 2019, most of the women completed their follow-up examination in 2016. Among the 391 Black women, 284 subsequently initiated treatment.
The characteristics of this subsample were similar to those reported for 391 women in the infertility sample.

Table 3: Patient Characteristics for Infertility Sample and Treatment Initiation Subsample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Infertility Sample (N=391)</th>
<th>Treatment Initiation Subsample (N=284)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infertility, in months</td>
<td>24 (12, 36)</td>
<td>24 (12,36)</td>
</tr>
<tr>
<td>Year of follow-up visit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>96 (24.6%)</td>
<td>68 (23.8%)</td>
</tr>
<tr>
<td>2016</td>
<td>105 (26.9%)</td>
<td>75 (26.4%)</td>
</tr>
<tr>
<td>2017</td>
<td>90 (23.0%)</td>
<td>63 (22.2%)</td>
</tr>
<tr>
<td>2018</td>
<td>71 (18.1%)</td>
<td>50 (17.6%)</td>
</tr>
<tr>
<td>2019</td>
<td>29 (7.42%)</td>
<td>28 (9.86%)</td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>28 (7.22%)</td>
<td>19 (6.76%)</td>
</tr>
<tr>
<td>Anxiety diagnosis</td>
<td>5 (1.38%)</td>
<td>5 (1.76%)</td>
</tr>
<tr>
<td>Depression diagnosis</td>
<td>6 (1.53%)</td>
<td>5 (1.76%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10 (2.56%)</td>
<td>4 (1.41%)</td>
</tr>
<tr>
<td>Thyroid disorder</td>
<td>16 (4.10%)</td>
<td>13 (4.59%)</td>
</tr>
<tr>
<td>Hypercolesterolemia</td>
<td>1 (0.26%)</td>
<td>1 (0.26%)</td>
</tr>
<tr>
<td>GYN-related characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fibroids</td>
<td>118 (30.18%)</td>
<td>82 (28.9%)</td>
</tr>
<tr>
<td>Endometriosis</td>
<td>28 (7.16%)</td>
<td>18 (6.34%)</td>
</tr>
<tr>
<td>PCOS</td>
<td>23 (5.91%)</td>
<td>15 (5.30%)</td>
</tr>
<tr>
<td>PID</td>
<td>4 (1.02%)</td>
<td>3 (1.06%)</td>
</tr>
</tbody>
</table>
Abnormal hormone test
- Abnormal Anti-Mullerian Hormone: 99 (26.1%) vs 74 (27.0%)
- Abnormal Follicle Stimulating Hormone: 70 (18%) vs 50 (17.7%)
- Abnormal Estradiol: 18 (4.63%) vs 14 (4.96%)
- Abnormal Luteinizing Hormone: 5 (1.29%) vs 5 (1.77%)

Female Contributory Factors
- Abnormal HSG or US: 207 (52.9%) vs 146 (51.41%)
- Ovulatory disorder: 134 (34.4%) vs 98 (34.5%)
- Tubal disorder: 142 (36.3%) vs 100 (35.2%)
- Unexplained infertility: 33 (8.53%) vs 25 (8.90%)
- Male factor: 172 (44%) vs 119 (41.9%)

Genetic screen
- Completed genetic screen: 166 (42.9%) vs 120 (42.7%)
- Abnormal result among those screened: 69 (41.6%) vs 47 (39.2%)

Median (25th, 75th percentile) for months of infertility; n (%) for categorical measures.

### 3.5.3 Psychobiological, Clinical, and Social Factors

Table 4 describes the psychobiological, clinical, and social characteristics of the 391 Black women in the infertility sample. In terms psychobiological factors, the mean age was 35.5 years old (range: 21 to 44), most (70.6%) were overweight or obese, 33.1% reported infertility for more than 12 months, 14.2% had at least one past medical history diagnosis, while 39.9% had one or more gynecological disorders.

<table>
<thead>
<tr>
<th>Table 4: Psychobiological, Clinical, Social Factors (N=391)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factors</td>
</tr>
<tr>
<td>Age, in years</td>
</tr>
<tr>
<td>Infertility greater than 12 months prior to seeking treatment</td>
</tr>
<tr>
<td>Overweight / Obese (BMI of greater than 25 kg/m²)</td>
</tr>
<tr>
<td>One of more comorbidities in past medical history</td>
</tr>
<tr>
<td>One or more gynecological disorders</td>
</tr>
</tbody>
</table>
Clinical Diagnostic Factors

One of more abnormal hormonal tests 139 (36.7%)
Primary infertility diagnosis 302 (77.2%)

Fertility Factors

Female-only Factor Infertility 178 (45.6%)
Male-only Factor Infertility 60 (15.4%)
Combination of Male & Female Factor 112 (28.7%)
Unexplained/Other Factor 40 (10.3%)

Clinical Treatment Plan

Oral medications only 16 (4.1%)
Injection medications only 19 (4.9%)
Combination of oral and injection medications 351 (90.0%)
IUI treatment 84 (21.5%)
IVF treatment 301 (77.0%)

Social Factors

Employed 356 (92.5%)
Qualifying insurance 294 (75.2%)

Mean ± Standard Deviation for age; n (%) for categorical measures. Comorbidities included:
Hypertension, Anxiety, Depression, Diabetes, Thyroid Disorders, Hypercholesterolemia; Total
gynecological disorders included: Fibroids, Endometriosis, Polycystic Ovarian Syndrome, Pelvic
Inflammatory Disorder.

Women experienced mostly primary fertility (77.2%) and 45.6% were diagnosed with female-only factor infertility. Most women’s recommended treatment plans included a combination of oral and injectable medication (90.0%), while most women required in vitro fertilization (IVF, 77.0%). A third (75.0%) of the sample possessed insurance with some level of infertility treatment benefit.

3.5.4 Fertility Treatment Outcomes

Table 5 summarizes the fertility treatment initiation and completion outcomes.

Of the 391 Black women evaluated, 284 (72.6%) initiated treatment for infertility. Of the
284 who initiated treatment, 258 (90.9%) completed the treatment plan. Among the 258 completers, 47 (18.2%) had positive serum pregnancy tests, 17 had live births (36.2%), with eight (17.0%) women still pregnant at the time of data abstraction.

Table 5: Fertility Treatment Outcomes

<table>
<thead>
<tr>
<th>Primary Outcomes</th>
<th>N</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiated treatment</td>
<td>391</td>
<td>284 (72.6%)</td>
</tr>
<tr>
<td>Among those who initiated treatment...</td>
<td>284</td>
<td></td>
</tr>
<tr>
<td>Completed treatment</td>
<td></td>
<td>258 (90.9%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary Outcomes</th>
<th>N</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Among those who completed treatment...</td>
<td>258</td>
<td></td>
</tr>
<tr>
<td>Positive Pregnancy Test (Serum HCG)</td>
<td></td>
<td>47 (18.2%)</td>
</tr>
<tr>
<td>Among those with pregnancy confirmed...</td>
<td>47</td>
<td></td>
</tr>
<tr>
<td>No birth</td>
<td></td>
<td>22 (46.8%)</td>
</tr>
<tr>
<td>Live birth</td>
<td></td>
<td>17 (36.2%)</td>
</tr>
<tr>
<td>Pending (Still Pregnant)</td>
<td></td>
<td>8 (17.02%)</td>
</tr>
</tbody>
</table>

N = Available data.

3.5.5 Predictors of Treatment Initiation

Table 6 shows the results of the 15 bivariate regression models. Notably, the odds of initiation of treatment were 2.1 times higher (aOR=2.1, p = 0.0029) in the women who had qualifying insurance coverage versus those who did not have qualifying insurance. Among this set of 15 predictor variables, qualifying insurance was the only significant predictor of treatment initiation in the full and final parsimonious model. In the full model, women with qualifying insurance had significantly greater odds of initiation of the recommended treatment plan than those without qualifying insurance.
(aOR = 1.977, 95% CI: 1.196, 3.268, p = 0.0079).
Table 6: Treatment Initiation: Bivariate Logistic Regression Results (N=391)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Explanatory Factors</th>
<th>Initiation Rate</th>
<th>p-value</th>
<th>OR</th>
<th>OR 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PB</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>--</td>
<td></td>
<td>0.7218</td>
<td>1.009</td>
<td>0.963, 1.057</td>
</tr>
<tr>
<td>More than 12 infertility months</td>
<td>183 (74.1%)</td>
<td>0.4345</td>
<td>1.201</td>
<td>0.759, 1.901</td>
<td></td>
</tr>
<tr>
<td>12 months or less (ref)</td>
<td>100 (70.4%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMI of greater than 25 kg/m²</td>
<td>202 (73.2%)</td>
<td>0.6673</td>
<td>1.112</td>
<td>0.685, 1.805</td>
<td></td>
</tr>
<tr>
<td>Below 25 kg/m² (ref)</td>
<td>81 (71.1%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One or more past medical diagnoses</td>
<td>39 (70.9%)</td>
<td>0.7963</td>
<td>0.920</td>
<td>0.490, 1.728</td>
<td></td>
</tr>
<tr>
<td>No diagnoses (ref)</td>
<td>241 (72.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One or more gynecologic diagnoses</td>
<td>108 (69.7%)</td>
<td>0.2684</td>
<td>0.775</td>
<td>0.493, 1.217</td>
<td></td>
</tr>
<tr>
<td>No diagnoses (ref)</td>
<td>175 (74.8%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CL</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary Infertility</td>
<td>216 (71.5%)</td>
<td>0.3648</td>
<td>0.776</td>
<td>0.448, 1.344</td>
<td></td>
</tr>
<tr>
<td>Secondary infertility (ref)</td>
<td>68 (76.4%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One or more abnormal levels</td>
<td>102 (73.4%)</td>
<td>0.7193</td>
<td>1.090</td>
<td>0.682, 1.743</td>
<td></td>
</tr>
<tr>
<td>No abnormality (ref)</td>
<td>172 (71.7%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fertility Factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unexplained</td>
<td>31 (77.5%)</td>
<td>0.4432</td>
<td>1.632</td>
<td>0.703, 3.785</td>
<td></td>
</tr>
<tr>
<td>Female only</td>
<td>134 (75.4%)</td>
<td>0.5586</td>
<td>1.443</td>
<td>0.855, 2.433</td>
<td></td>
</tr>
<tr>
<td>Male only</td>
<td>43 (71.7%)</td>
<td>0.7481</td>
<td>1.198</td>
<td>0.603, 2.383</td>
<td></td>
</tr>
<tr>
<td>Female and male (ref)</td>
<td>76 (67.9%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral medication only</td>
<td>13 (81.3%)</td>
<td>0.4441</td>
<td>1.645</td>
<td>0.460, 5.891</td>
<td></td>
</tr>
<tr>
<td>No (ref)</td>
<td>271 (72.5%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Injection medication only</td>
<td>15 (79.0%)</td>
<td>0.5403</td>
<td>1.422</td>
<td>0.461, 4.384</td>
<td></td>
</tr>
<tr>
<td>No (ref)</td>
<td>269 (72.5%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Combination oral &amp; injection eds</td>
<td>252 (71.8%)</td>
<td>0.1771</td>
<td>0.557</td>
<td>0.238, 1.303</td>
<td></td>
</tr>
<tr>
<td>No (ref)</td>
<td>32 (82.1%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intraterine Insemination - 1st plan</td>
<td>63 (75.0%)</td>
<td>0.5833</td>
<td>1.167</td>
<td>0.671, 2.030</td>
<td></td>
</tr>
<tr>
<td>Other (ref)</td>
<td>221 (72.0%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In vitro Fertilization – 1st plan</td>
<td>216 (71.8%)</td>
<td>0.4791</td>
<td>0.822</td>
<td>0.478, 1.414</td>
<td></td>
</tr>
<tr>
<td>Other (ref)</td>
<td>68 (75.7%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SC</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>258 (72.5%)</td>
<td>0.6855</td>
<td>1.185</td>
<td>0.522, 2.691</td>
<td></td>
</tr>
<tr>
<td>No (ref)</td>
<td>20 (69.0%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qualifying insurance</td>
<td>225 (76.5%)</td>
<td>0.0029</td>
<td>2.100</td>
<td>1.288, 3.424</td>
<td></td>
</tr>
<tr>
<td>No (ref)</td>
<td>59 (60.8%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.5.4 Predictors of Treatment Completion

The bivariate regression models indicated that age and abnormal hormone levels were significantly associated with treatment completion. The odds of completing treatment were 14% less among older women relative to younger women (OR: 0.876, 95% CI: 0.792, 0.969, p = 0.010). That is, younger women who initiated infertility treatment had the greatest probability of completing treatment. Women with at least one abnormal hormonal laboratory result prior to treatment initiation had lower odds of completing treatment than women who had no abnormal laboratory result prior to initiating treatment (OR: 0.429, 95% CI: 0.187, 0.986, p = 0.046). None of the other predictors significantly predicted completion in the bivariate model (all p > 0.05). Younger age was the only significant predictor in the full and final parsimonious model (p = 0.010).

3.6 Discussion

This study examined the psychobiological, clinical, and social factors among Black women who sought evaluation for infertility by a reproductive endocrinology specialist and initiated and completed recommended treatment. To the best of our knowledge, this is the first study to explore health-seeking behaviors among a cohort
Black woman seeking treatment for infertility. We abstracted variables from the electronic medical records of 391 Black women; these variables were reduced to 15 exposure variables. Bivariate and multiple regression analyses were performed to describe associations between exposure variables and treatment initiation. Further, we explored whether any of the exposures were associated with treatment completion. Overall, in the sample of 391 Black women who sought treatment for infertility, 72% of the women initiated the recommended treatment plan. Within those who initiated, 91% of the initiators completed the entire course of treatment. Although the majority of women initiated treatment, women with qualifying insurance had significantly higher odds of initiating treatment than those who did not have qualifying insurance. However, within the subsample of women who initiated treatment, women who were younger and women who had no abnormal hormones during the diagnostic evaluation had higher odds of completing treatment.

Due to limited racial/ethnic diversity in samples of previous studies examining initiation and discontinuation rates, it was difficult for us to compare the treatment initiation rates in our study to those of a comparable group. The treatment experiences of Black women are often discussed within minority groups of “Other.” Therefore, we utilize the limited literature to assume that the rate observed for initiation within our study was higher when compared to studies that report initiation rates of 65% for
Caucasian patients versus 15% of those listed as “Other” (Crawford et al., 2016).
Nevertheless, consistent with many studies that describe patient characteristics in treatment utilization for infertility, insurance coverage remains a salient factor among Black women for initiating treatment just as for Caucasian women in the United States (Dieke et al., 2017). Further, it is important to note that this higher rate of initiation among Black women can be associated with the location of the clinic being within a state with fertility treatment insurance mandates, which have been known to increase the uptake of infertility services (Adashi & Dean, 2017). Although the study supports the well-understood influence of insurance on initiation, our study showed that finances failed to influence completion of treatment. The odds of younger women completing treatment were higher, which was consistent with previous studies that showed that with each five-year increase, women had 77% higher odds of not initiating treatment in a majority Caucasian sample (Eisenberg et al., 2010). Other researchers have explored this effect of age on treatment completion and suggest there could be some correlation to poor prognosis (Dodge et al., 2017). In reproductive endocrinology, poor prognosis is often associated with baseline and prolonged abnormalities in hormones related to reproduction (Practice Committee of the American Society for Reproductive Medicine, 2015). The women in our study who initiated treatment were more likely to experience altered Anti-mullerian (27.0%) and Follicle stimulating (17.7%) hormones upon clinical
assessment. Both of these hormones are known to explain not only the quality of ovarian reserve, but are often used to predict responses to ovarian stimulation with treatment medication and, to a lesser extent, the likelihood for achieving a successful pregnancy with treatment (Practice Committee of the American Society for Reproductive Medicine, 2015). Previous work has shown that women who had higher basal follicle stimulating hormone levels were less likely to initiate treatment (Brandes et al., 2009). This effect was seen in the point bi-variate analysis, but the effect did not remain in the final model. This phenomenon should be further explored to determine what hormone may have contributed to lower association with treatment completion with a sample well-powered for this outcome.

There were other clinically relevant but non-significant results in this study that should be further elucidated. Interestingly, only 6% and 5% of the starting sample (N=391) had past medical history diagnoses of depression and anxiety, respectively. This incidence in psychological diagnoses is not typical of the Black population nationally where lifetime prevalence can be 10.4% for African Americans but lifetime persistence of chronic depression can be as high as 56.5% (Sohail et al., 2014). Further, women with infertility undergoing IVF are known to experience depression at rates as high as 28% (Pasch et al., 2012). This is a noteworthy finding because it highlights gaps in care pertaining to the mental wellbeing of Black women seeking and undergoing treatment.
for infertility. Crawford et al. (2016) and Eisenberg et al. (2010) noted that women who screened positive for depression had significant associations with failures to initiate treatment. Similarly, the psychological burden has also been a well-established factor in treatment completion (Gameiro et al., 2012). Although not significantly associated with treatment completion, the odds of completing treatment were 4.4 times higher in women who had one or more diagnosis in their past medical history. Many of these women could benefit from psychoemotional screenings at the initial visit to determine comprehensive care needs should they pursue treatment. With many more reproductive endocrinology centers having on-site mental health services, as was the case for the study site, there is the possibility of incorporating proactive mental health screening into the fertility evaluation and periodically during treatment. This, however, is not currently occurring.

Further, there are opportunities to explore the effects of treatment burden on completing the recommended treatment plan. Though not significant, women who were not on combination medications (meaning either solely on oral, injection, or no medications) were 3.4 times more likely to complete treatment than those who were on a combined medication protocol (OR: 0.293 for combination medication versus not, 95% CI: 0.038, 2.238). The treatment protocol for assisted reproductive technologies often require medications on strict timing schedules. This burden of care has also been
explored more in insured women where stress related to the burden of care was highly predictive of dropping out of IVF treatment (Domar et al., 2018).

Though rigorously designed, there were several limitations to this project. First, the study was a retrospective analysis of cross-sectional data, thereby limiting the ability to establish causation. In addition, generalizability is limited to one group of people living in a state with insurance mandates. Also, the study design could have been strengthened if there was a comparison group of Caucasian women to understand how differing variables interact with the outcomes between groups. Although the initial aim was well-powered, the variable of treatment completion was not accounted for when initial power calculations were being determined. However, the protocols for chart abstraction, the low amount of missing data, and high reliability of interrater agreement were strengths of this study. Moreover, a large limitation of this study is that we can only describe women who have initiated a consult, which limits generalizability. These factors may look different among Black women who have fertility issues and have sought treatment versus those who have not. Therefore, future research should investigate the characteristics of Black women who do not seek treatment.

Not only does this study add to the diversity of racial/ethnic groups represented in reproductive endocrinology science, it generated several hypotheses for future studies to examine the experiences of Black women who have challenges with infertility. First,
the sample explored in this study had a high initiation and completion rate, which challenges the assumptions that Black women are not utilizing services. However, further investigation is still needed to properly document the number of Black women who may be experiencing infertility and who are not seeking care and attempt to understand what factors influence them to not seek treatment, especially in regions where fertility mandates promote access to care. Also, further investigation should seek to extend the knowledge generated by this study to understand factors that influence treatment completion.

Future research should also aim to further investigate the psychological status of Black women who seek care by properly screening women at the onset of care and tracking these issues along the treatment trajectory. Policy development should be aimed at providing comprehensive medical coverage to women, especially those in marginalized groups to help reduce the effects of social determinants of health that lead to stratified reproductive services. General practitioners should explore additional screening of women for infertility symptoms as a mode of primary prevention of infertility to support early detection of infertility to promote completion and more positive responses to treatment.
4. Understanding Psychobiological, Clinical, and Sociocultural Factors that Influence Black Women with Infertility to Seek and Initiate Treatment: A Mixed Methods Study

4.1 Introduction, Theoretical Background, Research Approaches, and Specific Aims

Black women in the United States (U.S.) have twice the prevalence of infertility (14%) than non-Hispanic White women (7%) and are twice as less likely to seek treatment for family building (Chin et al., 2015; Dieke et al., 2017; Quinn, & Fujimoto, 2016; Shapiro et al., 2017; Chandra et al., 2013). In the U.S it is estimated that 7.4 million women in childbearing ages 15-44 have used some type of infertility services for family building, accounting for 12% of the total female population (CDC, 2019). It is known that up to 50% of White women with infertility will seek treatment with only half of these women are expected to follow through with recommended treatment plans (Chandra et al., 2013). The White women who do initiate treatment are often older, wealthy, highly educated, and married (Chin et al., 2015; Dieke et al., 2017; Quinn, & Fujimoto, 2016; Shapiro et al., 2017). The characteristics and rate of Black women with infertility who seek and initiate treatment are not well-documented and factors contributing to the disparities in health seeking have not been comprehensively explored.
Infertility has well-established consequences for women’s health contributing to depression, anxiety, distress, loss of control, and lower quality of life (Williams, 1997; Cousineau & Domar, 2017; Domar et al., 1993). The consequences of infertility become particularly crucial to address in the Black community as childbearing is a culturally central component of Black families (Hill, 2001). Though not explored in Black communities, the advantages of seeking and initiating infertility treatment are positive even if treatment is unsuccessful in other groups. The positive outcomes include increased self-confidence, decreased stress, and increased joy (Ranjbar et al., 2015) along with increased gratitude (Ladores & Arojan, 2015). Similarly, women who experienced stress and anxiety during infertility treatment often experienced progressive improvements with mental health markers after successful conception (Velikonja et al., 2016).

The literature shows that the factors influencing treatment seeking for infertility can come with multi-dimensional facilitators and barriers. Facilitators and barriers to treatment seeking were explored in Chapter 2. Facilitators for undergoing evaluation for reproductive endocrinology issues were associated with perceived symptom salience, low self-esteem, life satisfaction, and importance of parenthood. Common barriers included clinician related concerns, lack of fertility awareness, a depression diagnosis, and understanding of treatment options. However, studies were limited in design
quality, sample diversity, and comprehensiveness of data collection. Further, the current literature on treatment initiation has shown that older age, education, financial concerns, and depressive symptoms are known to influence whether women initiate a recommended treatment plan for infertility (Eisenberg et al., 2010; Crawford et al., 2017). However, like treatment seeking, factors contributing to treatment initiation has predominately been explored in samples of majority White, educated, and wealthy White women in the U.S (Crawford et al., 2017).

The studies that explore influences in treatment seeking and initiation among Black women who experience infertility are limited in scope and perspective. However, they suggest that Black women may have different experiences during the health seeking process for infertility than Non-Hispanic White women. For example, Black women with infertility were more likely to have self-referred for treatment, perceived racial discrimination, and had negative patient-provider interactions (Ceballo et al., 2015; Bell, 2016). Further, Black women and other minority groups experience sociocultural barriers like internalized stigma, lower social support, and inadequate health literacy surrounding infertility which can limit their uptake and utilization of services (Nachtigall et al., 2009; Bell, 2014). Additionally, these studies often focused on Black women who were from lower socioeconomic backgrounds, in limited access communities, and women who did not seek treatment for infertility. Although costs may
contribute to decreased treatment seeking, in the 16 states adopting state mandated fertility treatment coverage (Schmidt, 2007; Buckles, 2013; Mattocks et al., 2015), Black women continue to lag behind in infertility utilization.

As the disparities in treatment seeking and initiation remains an issue for many women Black women in the U.S, there seems to be additional unmet needs beyond providing safe, accessible, and affordable options for infertility treatment options to reduce the devastating effects of this damaging disease. Therefore, the purpose of this study is to explore facilitators and barriers influencing the health seeking process among Black women who seek and undergo evaluations for infertility.

4.1.1 Theoretical Framework

A theoretical framework adapted from literature on treatment seeking and Chrisman’s Health Seeking Process Model guided this study (Chrisman, 1977). The Chrisman’s Health Seeking Process model explores the relationship of sociocultural imperatives of everyday life affecting patterns of health beliefs and practices through its five conceptual domains: symptom definition, illness-related shifts in role behavior, lay consultation and referral, treatment actions, and treatment completion. These domains integrate the biological, clinical, psychological, social, and cultural factors that form the
complex environments in which individuals pursue evaluations and to the degree in which they act and adhere to treatment recommendations.

Figure 4 posits that there are multidimensional factors and perceptions that are in relationship with one another and are continuous throughout the process of health seeking from the onset of symptoms, to an evaluation by a reproductive endocrinologist,
and subsequent treatment actions taken to initiate and complete the recommended treatment plan. The stage of initial evaluation is starred because not every woman will seek primary evaluation from general practitioners prior to meeting with reproductive endocrinology. The culmination of these psychobiological, clinical, and sociocultural dimensions merge to predict behaviors related to treatment seeking, initiation of the recommended treatment plan, and treatment completion.

4.1.2 Mixed Methods Approach

The following study utilized a convergent mixed methods design using data from a retrospective chart review and semi-structured interviews from Black women who sought treatment for infertility. The study defined mixed methods as an opportunity for multiple ways of seeing and understanding Black women who experience infertility as they navigate potential psychobiological, clinical, and sociocultural barriers and facilitators to care (Greene et al., 2005). This definition pulls from paradigmatic definitions traditionally utilized by mixed methodologists in realms of social inquiry where guiding assumptions call for greater diversity in ideas, perspective, and conceptual development of meaning (Johnson et al., 2007).

Therefore, this study welcomed and included the description of multiple realities by combining constructivist and pragmatic approaches that shaped the methodological design, data collection, and analysis procedures of this study (Creswell & Plano Clark,
The constructivist approach helped build our understanding of this population through semi-structured interviews and analysis of retrospective chart data. Constructivism was defined as knowledge and meaning constructed by participants as a result of their experiences through varying social interactions (Given, 2008). The use of open-ended questions for the qualitative portion and collecting a broad range of variables in the chart review aligned with this approach. Therefore, the understanding of these experiences was co-constructed between inquirer and participant in the qualitative analysis and we heavily opposed the view that a single objective meaning existed as we reported both statistically significant and non-significant quantitative data (Given, 2008). Therefore, the findings of both data types were used to generate holistic understandings, highlight typical and atypical experiences, and provide a theoretical basis for further inquiry of Black women who experience infertility (Marshall & Rossman, 2014; Shannon-Baker, 2016; Creswell & Plano Clark, 2018).

The pragmatic approach was applied to how we formed specific aims, analyzed, and merged both types of data, and considered future applicability of our findings to improve the health seeking process for Black women experiencing infertility. For this study, the pragmatic approach posits there are many different methods to achieve results that are meaningful and such meaningful knowledge can provide a direct pathway to finding potential solutions (Creswell & Plano Clark, 2018; Shaw et al., 2010).
For the qualitative portion, descriptive interviews (Marshall & Rossman, 2014), values coding (Saldaña, 2015), and thematic analysis (Saldaña, 2015; Vaismoradi et al., 2013) were appropriate methods to highlight what influences were most meaningful to participants. Additionally, this guided the use of merging quantitative and qualitative data as an integration technique (Fetters et al., 2013) to provide a comprehensive and practical understanding of Black women’s health seeking experience. This comprehensive understanding could then help identify gaps in practice, policy, and research that potentially reduce disparities that disproportionately affect Black women with infertility (Creswell & Plano Clark, 2018; Marshall & Rossman, 2014; Johnson et al., 2007).

A mixed methods approach in health sciences research has been well-suited for investigating complex, multilevel processes, and systems (Fetters et al., 2013). Using a mixed methods approach for this study created a larger and broader view of Black women through integrating quantitative and qualitative data to accurately construct our understanding of convergent and divergent themes and relationships (Creswell & Plano Clark, 2018). Previous research had failed to show a complete understanding of the patterns and practices of Black women who experiencing infertility because it often relied on using only one type of data. Therefore, the purpose of this study was to utilize two types of data to achieve the study aims that could not be answered with one
approach alone (Shannon-Baker, 2016). Using the two types of data can help in leveraging/reducing the limitations of each type of design (Fetters et al., 2013; Creswell & Plano Clark, 2018) and also provide a robust theoretical and conceptual basis for future studies involving Black women who experience infertility. Since many reproductive endocrinology-focused studies lack adequate samples of Black women, therefore, limiting generalizability and transferability to Black women (Greil et al., 2011; McCarthy & Chiu, 2011; White et al., 2006), the specific aims of this study are to:

Aim 1. Discuss the findings of Chapter 3 where we described the characteristics of Black women seeking treatment for infertility and reported the psychobiological, clinical, and social factors that influenced initiation of the recommended infertility treatment plan following the reproductive endocrinology evaluation.

Aim 2. Discuss the psychobiological, clinical, and sociocultural perspectives of Black women who seek treatment for infertility and then describe the psychobiological, clinical, and sociocultural perceptions that influenced initiation of the recommended treatment plan.

Aim 3. Integrate results and themes identified from quantitative and qualitative data to provide a comprehensive multidimensional description and conceptualization of the psychobiological, clinical, and sociocultural experiences of Black women who seek and initiate treatment for infertility.
4.2 Methods

4.2.1 Design

We assessed the psychobiological, clinical, and sociocultural influencing Black women with infertility using a convergent parallel mixed methods study design (Creswell & Plano Clark, 2018). The study integrated retrospective chart review findings (quantitative) explored in dissertation aim 3 (Chapter three) and data from a one-time semi-structured interview (qualitative) with Black women who underwent a reproductive endocrinology evaluation. Institutional review board approval for this study was obtained at Duke University Health System with permission from the private fertility clinic’s research team. The fertility clinic is a privately own entity with no academic affiliation; therefore, study procedures and conduct were reviewed and approved by the researcher’s primary institution.

4.2.2 Setting

Recruitment for the quantitative and qualitative portions were both conducted at a large infertility clinic in a metropolitan area on the east coast of the U.S. The location of this clinic was selected because it was situated in a state with active insurance mandates to cover infertility treatment services. In addition to its main facility, there are nearly a dozen other satellite offices in the same state. The private infertility center includes a large group of physicians, advanced practice providers, nurses, and technicians, and a
full-service on-site hematology, embryology, and andrology lab. The clinic offers broad and comprehensive services such as treatment for male and female factor infertility, treatment for single and partnered men and women, third party services (gestational carriers, donor eggs), cryopreservation, pre-genetic testing and screenings, and mental health services.

4.2.3 Samples

Eligible women for both data types had the same inclusion and exclusion criteria. Inclusion criteria were women who self-identified as African American/Black, between the ages of 18 and 44 years old, who presented for an initial infertility evaluation with a male partner between January 2015 and September 2019. Although male partners did not need to be present at the initial evaluation, diagnostic results would need to specify women were seeking treatment with a male partner. Because only 16 states include infertility treatment as mandated in private health insurance, women who were seen at any of the infertility center’s offices that were in the same state as its main facility were included. Women excluded from the study were single or unpartnered women, women who sought fertility cryopreservation, or women seeking conception services who were in a same-sex partnership. We excluded these groups because they may experience additional or different factors that influence treatment seeking and initiation.
4.2.4 Quantitative Measures & Data Collection

We generated a query of all visits by Black women who had a reproductive endocrinology visit at the infertility clinic between January 2015 to September 2019 (N=8200). Following the identification of 3326 individual patient records during this time frame, SAS™ software (Cary, NC) was used to assign each a unique random identification (random ID) using a random number generator. The random ID assigned to each patient was sorted in ascending order. Charts were reviewed one by one in sequential order by random ID and each sequential visit record was screened for study eligibility based on the inclusion and exclusion criteria. The first 391 patient records that met the eligibility criteria were included in the infertility sample. A primary abstractor completed the manual abstraction of the study variables for all 391 patients. To assess whether each patient had initiated infertility treatment, the cohort was followed for three months from the time of the first follow-up visit. The comprehensive list of measures collected for the quantitative portion are detailed in Table 7.

Table 7: Psychobiological, Clinical, and Social Measures for Retrospective Chart Review

<table>
<thead>
<tr>
<th>Psychobiological Factors</th>
<th>Description/definition</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Numerical age of the patient seeking treatment</td>
<td>18-44</td>
</tr>
<tr>
<td>Months Experiencing Infertility</td>
<td>Time in months the patient waited to seek treatment for infertility</td>
<td>Continuous</td>
</tr>
<tr>
<td>Overweight/Obese</td>
<td>Body mass index (BMI) of greater than 25 kg/m²</td>
<td>0 = No, 1=Yes</td>
</tr>
<tr>
<td>Year</td>
<td>Year the patient completed their follow up visit where</td>
<td>2015, 2016, 2017,</td>
</tr>
</tbody>
</table>
treatment plan was presented 2018, 2019

**Total Comorbidities**
Past medical history included one or more of the following diagnoses:
- Hypertension Diagnosis: 0=No, 1=Yes
- Anxiety Diagnosis: 0=No, 1=Yes
- Depression Diagnosis: 0=No, 1=Yes
- Diabetes: 0=No, 1=Yes
- Thyroid Abnormality: 0=No, 1=Yes
- Hypercholesterolemia: 0=No, 1=Yes

**Gynecological History**
Past gynecological history included one or more of the following diagnoses:
- Uterine fibroids: 0=No, 1=Yes
- Endometriosis: 0=No, 1=Yes
- Polycystic Ovarian Syndrome: 0=No, 1=Yes
- Pelvic inflammatory disease: 0=No, 1=Yes

<table>
<thead>
<tr>
<th><strong>Clinical Factors</strong></th>
<th><strong>Description/definition</strong></th>
<th><strong>Coding</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic Screen</td>
<td>Patient completed screen for genetic disorders</td>
<td>0=No, 1=Yes, Normal, 2=Yes, Abnormal</td>
</tr>
<tr>
<td>Abnormal Labs</td>
<td>At least one abnormal hormone related to ovulation:</td>
<td>0=None, 1=1 or more</td>
</tr>
<tr>
<td></td>
<td>Luteinizing Hormone</td>
<td>0=Normal, 1=Abnormal</td>
</tr>
<tr>
<td></td>
<td>Progesterone</td>
<td>0=Normal, 1=Abnormal</td>
</tr>
<tr>
<td></td>
<td>Prolactin</td>
<td>0=Normal, 1=Abnormal</td>
</tr>
<tr>
<td></td>
<td>Anti-Mullerian Hormone (AMH)</td>
<td>0=Normal, 1=Abnormal</td>
</tr>
<tr>
<td>Primary Infertility</td>
<td>Whether patient presented could not conceive AND achieve livebirth for the first time:</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Female Factor-Only Infertility</td>
<td>As a result of abnormal anatomy (shown by ultrasonography (US), hysterosalpingogram (HSG), or magnetic resonance imaging), abnormal hormones, or other reported underlying female-related issue.</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Male Factor-Only Infertility</td>
<td>Presence of abnormal semen analysis or other reported underlying male-related issue</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Combined Factor</td>
<td>Infertility results from a combination of female-related and male-related issues</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Unexplained Factor</td>
<td>An identifiable cause for infertility could not be determined</td>
<td>0=No, 1=Yes</td>
</tr>
</tbody>
</table>

**Recommended Treatment Plan**
- Oral Medication Only: Recommended treatment plan includes the use of only oral medications 0=No, 1=Yes
- Intramuscular Injection: Recommended treatment plan includes the use of only intramuscular injections 0=No, 1=Yes
- Combination of Oral and: Recommended treatment plan includes both the use of...
Intramuscular Medications | oral and intramuscular medications |
Intrauterine Insemination | Recommended treatment plan is for intrauterine insemination |
In-vitro Fertilization/ICSI | Recommended treatment plan is for in-Vitro Fertilization |

<table>
<thead>
<tr>
<th>Social Factors</th>
<th>Description/definition</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>Employed either full-time or part-time</td>
<td>0= No, 1=Yes</td>
</tr>
<tr>
<td>Qualifying Insurance</td>
<td>Whether the primary insurance listed contained infertility treatment benefits</td>
<td>0= No, 1=Yes</td>
</tr>
</tbody>
</table>

For quality assurance, we randomly selected 7.5% of 391 charts (N=30 charts) to assess inter-rater reliability (Libby et al., 2011) of the data abstraction and coding process. A second reviewer re-abstracted the predefined set of study variables for the 30 patients. We set our quality threshold for reliability as a kappa coefficient of 0.70 per variable.

4.2.5 Qualitative Recruitment & Data Collection

Thirteen Black women who sought treatment for infertility at this clinic were recruited to complete a one-time semi-structured interview. Eligible research participants were recruited through emails directly from research staff, online advertisement on the clinic’s website, community events, and social media distribution. Participants had the option to complete the recorded interviews in person or over the phone. Interviews were scheduled at their earliest convenience and participants were compensated for their time in completing a short demographic survey and the interview.
The study aimed to purposively sample an equal portion of women who did and did not initiate infertility treatment after seeking an evaluation with the reproductive endocrinologist and were presented with a treatment plan. Based on previous literature that examined factors influencing health seeking for infertility, there has been no consensus on the number of Black women to be interviewed to achieve theoretical saturation. Therefore, we agreed on a target sample of 20 women to be interviewed, 10 who initiated treatment and 10 who did not. In order to remain consistent with the coding process, transcripts were reviewed in groups of 3 until no new themes emerged (Javadi & Zarea, 2016; Elo et al., 2014). Saturation was achieved at 12 interviews, however, recruitment continued until the end of that calendar month. Therefore, a total of 13 interviews were included in the final sample, 6 women who initiated treatment and 7 women who did not initiate treatment.

The study team consisted of 1 primary investigator and 4 student research assistants. All participants were interviewed by the primary investigator along the medium of their choice. One participant chose an in-person interview, while the remaining twelve women were interviewed over the phone. At the start of each interview the interviewer explained the project, answered the participant’s questions, asked for the participant’s consent to take part in the study and have their responses audio recorded. Participants then completed a short demographic survey that collected
non-identifiable information regarding the participant’s age, length of time experiencing infertility, and sociodemographic factors such as income, education, and employment. Participants were offered $35 for their time and efforts in the study and were asked to select a pseudonym of their choice.

We developed a semi-structured interview guide with a series of open-ended questions and probes to elicit information. Interview questions were determined and developed a priori based on previous literature review that examined barriers and facilitators to treatment seeking and initiation. The guide explored personal experiences during the pre-treatment period and further investigated if and how perceptions of infertility, patient-provider interactions, treatment plans, partner/peer involvement, financial considerations, faith, or education influenced treatment decisions (see Table 8 for examples). Based on the interviewee, questions were framed on whether factors influenced treatment initiation or treatment non-initiation. The guide allowed the interviewer to maintain consistency in data collection, however, other factors relevant to treatment seeking and initiation were welcomed and explored as they emerged within individual interviews. Though some women completed several rounds of treatment or eventually sought treatment at other facilities following their evaluation at the study’s recruitment facility, the main emphasis of the interviews was regarding their initial
experiences at the large infertility clinic. Interviews lasted between 25 and 80 minutes and were recorded using an encrypted recorder.

Table 8: Semi-structured Interview Protocol Sample Questions

<table>
<thead>
<tr>
<th>Psychobiological Factors</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What initially alarmed you to know that you needed help (to conceive)?</td>
<td></td>
</tr>
<tr>
<td>Tell me about how your inability to have a child (at that point) impacted your life?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical Factors</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>How was your experience in your first visit with Shady Grove?</td>
<td></td>
</tr>
<tr>
<td>What did you think about your proposed treatment plan?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sociocultural Factors</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Explain the role your partner played in your decisions of regarding treatment</td>
<td></td>
</tr>
<tr>
<td>Do you believe your level of education played a role in your decision regarding treatment?</td>
<td></td>
</tr>
</tbody>
</table>

Upon the completion of each interview, the interviewer completed a detailed memo of the interaction of the visit for the purpose of bracketing. Bracketing is a method used to mitigate the effects of preconceptions to increase the rigor of a study (Tufford & Newman, 2012). The method of bracketing was used to decrease any potential bias from incorporating preconceptions, assumptions, and emotions in the coding process. Within bracketing, the interviewer reflected on the social, cultural, and historical factors that influence interpretation. This was particularly useful as the interviewer shared the same racial/ethnic identification with the participants. The memos were not included in the final analysis of the study.
4.2.6 Quantitative Data Analysis

Descriptive statistics were used to detail the psychobiological, clinical, and social characteristics of those who sought a reproductive endocrinology evaluation and those who initiated treatment. Outcomes of those who completed treatment were also reported. Non-directional statistical tests were performed with the level of significance at 0.05 per test. The significance level was not adjusted for multiple outcomes or tests due to the exploratory nature of this study. Data were analyzed using SAS version 9.4™ software. Bivariate and multivariable logistic regression models were used to examine the influence of these factors on initiation of infertility treatment within three months. The initial multivariable model included five psychobiological, 8 clinical, and two social factors (factors described in Table 5). A backward elimination variable selection method was then used to reduce the initial multivariable model to a final parsimonious model that included only those factors significant at the 0.05 level. Odds ratios (ORs) for bivariate analyses and adjusted odds ratios (aORs) for multivariable models and their 95% CIs were reported to estimate effect sizes and address clinical relevance.

4.2.7 Qualitative Coding and Analysis

Interview transcripts were digitally transcribed verbatim and checked for accuracy by the primary investigator and a second member of the research team. Transcripts were uploaded into QSR International’s NVivo 12 software. In the first stage
of analysis, attribute and descriptive coding schemes were used as a first cycle coding. The attribute coding was completed to provide general information about the general characteristics of the participants, namely the treatment group (initiator versus non-initiator) and information collected from the demographic surveys such as: length of time experiencing infertility, income, age group, and responses to the semi-structured interview questions. Then, descriptive coding was used to describe the main ideas and responses that emerged. From these ideas, values coding was then used as the second cycle coding method for the qualitative portion of this study. Values coding is an Affective Method of coding that allows for understanding individual perspectives by intentionally investigating their human experience (Saldaña, 2015). Values coding reflected the participant’s values, attitudes, and beliefs. As the overall aim of the study was to explore the multidimensionality of Black women’s treatment experiences, it became crucial to use Values coding to help report the possibly interconnected and complex elements. It was understood that these elements are formed and influenced through social interactions and institutions, and cultural/religious memberships and are constantly working simultaneously influencing the health seeking process for infertility (Chrisman, 1977; Saldaña, 2015). Finally, thematic analysis was used for explaining and describing the findings. Thematic analysis was an ideal type of analytic method as it a flexible tool that provides a rich and detailed account of major themes (Vaimoradi et al.,
Themes are defined as groups of data that share a coherent meaning when integrated (Vaismoradi, et al., 2013; Javadi & Zarea, 2016).

The number of transcripts to code by multiple reviewers is often disputed in the social science literature. Cited recommendations range from as few as 3 transcripts to as large as 25% of the transcripts (MacPhail et al., 2015). Since there was one researcher who read through all the transcripts, we followed the following process for coding and rating interrater reliability by Campbell, Quincy, Osserman, and Pederson (2013). The primary researcher developed the initial coding scheme with definitions grouped into categories. A second coder was brought in to complete descriptive coding and codes were discussed and definitions clarified. Within the first group of 3 transcripts, one transcript was selected at random for the second coder to code. If the Cohen Kappa for intercoder reliability was between .40-.60 (MacPhail et al., 2015), satisfactory intercoder reliability was achieved. If they were lower than this value, coding schemes would be discussed again and modified as necessary and the 3 transcripts would be recoded by both the researchers again until satisfactory reliability was achieved (Campbell et al., 2013). Once satisfactory agreement was achieved, the second reviewer coded 25% of the remaining transcripts.
4.2.8 Integration Analysis

Parallel-databases variant was the type of strategy used to combine the two types of databases to give a complete picture of Black women and their experiences initiating treatment. This strategy is applied by merging the two types of data at the final step after both data types have been individually analyzed and interpreted (Creswell & Plano Clark, 2018). It is one of the common integration strategies for data collection and analysis for convergent design studies. In this study, this integration strategy was shown by the use of joint displays. Joint displays are a visual representation of merging linked quantitative and qualitative data (Creswell & Plano Clark, 2018) and are an innovative method in mixed methods analysis where both types of data are displayed side by side to compare results (Guetterman, Fetters, & Creswell, 2015). The joint displays can be visualized through tables, matrices, or figures (Fetters et al., 2013). Utilizing this method to juxtapose the findings is favorable because it practically shows the authors interpretation and the findings that supported the study’s claims (Plano Clark & Sanders, 2015). Joint displays can be helpful in merging convergent findings; however, they also may imply the need for further analysis of divergent results by relooking at one type of data or through future study development (Creswell & Plano Clark, 2018). If there was evidence of discordant findings, researchers examined potential sources of bias, methodological assumptions, or procedure errors (Fetters et al., 2013). However,
with utilizing a pragmatic approach to guide the integrative process, there were opportunities where an attempt to find meaning in both concordant and discordant findings was imposed and appropriate (Shannon-Baker, 2016).

This study utilized two tables that reported several key findings from the quantitative data from descriptive statistics, bivariate analyses, and the final logistic model from Chapter 3. They were shown juxtapose to the final thematic findings reported from the qualitative interviews. We categorized the themes and discussed how themes within the psychobiological, clinical, and social domains were similar, different, and what kinds of relationships may exist between the variables themselves and in relation to the quantitative findings (Saldaña, 2015). Finally, a third column provided an integrative summary of the mixed methods analysis.

4.3 Findings

4.3.1 Quantitative Results

Among all those who sought infertility the mean age was 35.5 years old. These women tended to be overweight or obese with body mass index scores of 25 kg/m² or higher (63.5%), and comprehensive testing revealed more structurally associated abnormalities on the female exam, most notably fibroids (30.2%) and tubal disorders (36.3%). Women experienced mostly primary fertility (77.2%), of female factor only origin (45.6%), and most were recommended to have a treatment plan that included a
combination of oral and injectable medication (90.0%) and in vitro fertilization (77.0%).

Median time from onset of infertility symptoms to initial evaluation was 24 months.

Although we could not account for the entire year of 2019, most of the women completed their follow up examination in 2016. Variables were collapsed into 15 exposure variables and the findings are shown in Table 9.

**Table 9: Psychobiological, Clinical, Social Factors of Black Women who Sought Treatment (N=391)**

<table>
<thead>
<tr>
<th>Factors</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Psychobiological Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Age, in years</td>
<td>35.5 ± 4.8</td>
</tr>
<tr>
<td>Infertility greater than 12 months prior to seeking treatment</td>
<td>121 (33.1%)</td>
</tr>
<tr>
<td>Overweight / Obese (BMI of greater than 25 25 kg/m²)</td>
<td>276 (70.6%)</td>
</tr>
<tr>
<td>One of more comorbidities in past medical history</td>
<td>55 (14.2%)</td>
</tr>
<tr>
<td>One or more gynecological disorders</td>
<td>155 (39.9%)</td>
</tr>
<tr>
<td><strong>Clinical Diagnostic Factors</strong></td>
<td></td>
</tr>
<tr>
<td>One of more abnormal hormonal tests</td>
<td>139 (36.7%)</td>
</tr>
<tr>
<td>Primary infertility diagnosis</td>
<td>302 (77.2%)</td>
</tr>
<tr>
<td><strong>Fertility Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Female-only Factor Infertility</td>
<td>178 (45.6%)</td>
</tr>
<tr>
<td>Male-only Factor Infertility</td>
<td>60 (15.4%)</td>
</tr>
<tr>
<td>Combination of Male &amp; Female Factor</td>
<td>112 (28.7%)</td>
</tr>
<tr>
<td>Unexplained/Other Factor</td>
<td>40 (10.3%)</td>
</tr>
<tr>
<td><strong>Clinical Treatment Plan</strong></td>
<td></td>
</tr>
<tr>
<td>Oral medications only</td>
<td>16 (4.1%)</td>
</tr>
<tr>
<td>Injection medications only</td>
<td>19 (4.9%)</td>
</tr>
<tr>
<td>Combination of oral and injection medications</td>
<td>351 (90.0%)</td>
</tr>
<tr>
<td>IUI treatment</td>
<td>84 (21.5%)</td>
</tr>
<tr>
<td>IVF treatment</td>
<td>301 (77.0%)</td>
</tr>
<tr>
<td><strong>Social Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>356 (92.5%)</td>
</tr>
<tr>
<td>Qualifying insurance</td>
<td>294 (75.2%)</td>
</tr>
</tbody>
</table>
Mean ± Standard Deviation for age; n (%) for categorical measures. Comorbidities included: Hypertension, Anxiety, Depression, Diabetes, Thyroid Disorders, Hypercholesterolemia; Total gynecological disorders included: Fibroids, Endometriosis, Polycistic Ovarian Syndrome, Pelvic Inflammatory Disorder.

Of the 391 Black women in the final sample, a total of 284 (72.6%) women initiated treatment for infertility and they revealed similar characteristics among all three domains. 254 (90.9%) of Black women completed the treatment plan resulting in 47 (18.2%) positive serum pregnancy tests, 17 live births (36.2%), with 8 (17.02%) women still pregnant at the time of data abstraction.

Table 10 shows the results of the bivariate regressions involving each explanatory variable with the primary outcome: initiating treatment. Of all the explanatory variables, the odds of initiation of treatment were statistically significantly 2.1 times higher (Wald $\chi^2 = 8.85$, df = 1, $p = 0.0029$, 95% CI: 1.288, 3.424) in the women who had qualifying insurance coverage versus those who did not have qualifying private health insurance. After inputting all 15 variables in the initial model, the final regression showed that when predicting initiation (Wald $\chi^2 = 7.06$, df = 1, $p = 0.0079$), women with qualifying insurance had significantly higher odds of initiation of the recommended treatment plan than those without qualifying insurance (aOR = 1.977, 95% CI: 1.196, 3.268).

Table 10: Treatment Initiation: Bivariate Logistic Regression Results (N=391)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Explanatory Factors</th>
<th>Initiation Rate</th>
<th>p-value</th>
<th>OR</th>
<th>OR 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PB</td>
<td>Age</td>
<td>--</td>
<td>0.7218</td>
<td>1.009</td>
<td>0.963, 1.057</td>
</tr>
<tr>
<td></td>
<td>More than 12 infertility months</td>
<td>183 (74.1%)</td>
<td>0.4345</td>
<td>1.201</td>
<td>0.759, 1.901</td>
</tr>
</tbody>
</table>
12 months or less (ref) & 100 (70.4%) 
BMI of greater than 25 kg/m² & 202 (73.2%) & 0.667 & 1.112 & 0.685, 1.805 
Below 25 kg/m² (ref) & 81 (71.1%) 
One or more past medical diagnoses & 39 (70.9%) & 0.796 & 0.920 & 0.490, 1.728 
No diagnoses (ref) & 241 (72.6%) 
One or more gynecologic diagnoses & 108 (69.7%) & 0.268 & 0.775 & 0.493, 1.217 
No diagnoses (ref) & 175 (74.8%) 

<table>
<thead>
<tr>
<th>CL</th>
<th>Primary Infertility</th>
<th>216 (71.5%)</th>
<th>0.3648</th>
<th>0.776</th>
<th>0.448, 1.344</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Secondary infertility (ref)</td>
<td>68 (76.4%) &amp; 0.7193</td>
<td>1.090</td>
<td>0.682, 1.743</td>
<td></td>
</tr>
<tr>
<td></td>
<td>One or more abnormal levels</td>
<td>102 (73.4%)</td>
<td>0.7193</td>
<td>1.090</td>
<td>0.682, 1.743</td>
</tr>
<tr>
<td></td>
<td>No abnormality (ref)</td>
<td>172 (71.7%)</td>
<td>0.7193</td>
<td>1.090</td>
<td>0.682, 1.743</td>
</tr>
</tbody>
</table>

Fertility Factors

Unexplained & 31 (77.5%) & 0.4432 | 1.632 | 0.703, 3.785 |
Female only & 134 (75.4%) & 0.5586 | 1.443 | 0.855, 2.433 |
Male only & 43 (71.7%) & 0.7481 | 1.198 | 0.603, 2.383 |
Female and male (ref) & 76 (67.9%) | 0.7481 | 1.198 | 0.603, 2.383 |
Oral medication only & 13 (81.3%) & 0.4441 | 1.645 | 0.460, 5.891 |
No (ref) & 271 (72.5%) | 0.4441 | 1.645 | 0.460, 5.891 |
Injection medication only & 15 (79.0%) & 0.5403 | 1.422 | 0.461, 4.384 |
No (ref) & 269 (72.5%) | 0.5403 | 1.422 | 0.461, 4.384 |
Combination oral & injection eds & 252 (71.8%) & 0.1771 | 0.557 | 0.238, 1.303 |
No (ref) & 32 (82.1%) | 0.1771 | 0.557 | 0.238, 1.303 |
Intrauterine Insemination - 1st plan & 63 (75.0%) & 0.5833 | 1.167 | 0.671, 2.030 |
Other (ref) & 221 (72.0%) | 0.5833 | 1.167 | 0.671, 2.030 |
In vitro Fertilization – 1st plan & 216 (71.8%) & 0.4791 | 0.822 | 0.478, 1.414 |
Other (ref) & 68 (75.7%) | 0.4791 | 0.822 | 0.478, 1.414 |

SC

Employed & 258 (72.5%) & 0.6855 | 1.185 | 0.522, 2.691 |
No (ref) & 20 (69.0%) | 0.6855 | 1.185 | 0.522, 2.691 |
Qualifying insurance & 225 (76.5%) & 0.0029 | 2.100 | 1.288, 3.424 |
No (ref) & 59 (60.8%) | 0.0029 | 2.100 | 1.288, 3.424 |

OR = odds ratio; CI = confidence interval; ref = reference group; age = continuous variable entered in model in descending order (oldest to youngest); PB=Psychobiological, CL=Clinical, SC=Social.
4.3.2 Qualitative Results

A total of 13 women completed a one-time interview for this study. Six women initiated treatment within 3 months of being presented the recommended treatment plan and 7 women did not initiate treatment with the same time frame. A description of the women is found in Table 11 with all of their pseudonyms in the order that their interviews were conducted. Within the 6 women who initiated all but two completed treatment. One could not complete due to poor ovarian stimulation (Joy), and one had just begun the process of treatment initiation at the time of the interview (Ella). Of the 7 women who did not initiate treatment, 3 women eventually began treatment for their infertility concerns, 2 of whom began outside of the study’s recruitment center. Ages of the women ranged from 32 to 44 years old. Most participants were married (n=11), highly educated with at least a graduate level degree (n=11) and worked full time (n=13). The time from first onset of fertility symptoms to seeking treatment ranged from 1 month to 10 years (< 12 months, n=2). Table 11 provides a description of the individual participant characteristics.

Table 11: Individual Features of Interview Participants (N=13)

<table>
<thead>
<tr>
<th>No.</th>
<th>Group</th>
<th>Name</th>
<th>Age</th>
<th>Income</th>
<th>Education</th>
<th>Religious Beliefs</th>
<th>Duration</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Initiator</td>
<td>Beyonce</td>
<td>36</td>
<td>&gt;$100k</td>
<td>G/P</td>
<td>Catholic</td>
<td>24 months</td>
<td>Secondary Infertility, Unexplained</td>
</tr>
<tr>
<td>2</td>
<td>Initiator</td>
<td>Meg</td>
<td>37</td>
<td>&gt;$100k</td>
<td>Some College College</td>
<td>Christian</td>
<td>1 month</td>
<td>Bilateral Tubal Removal</td>
</tr>
<tr>
<td>3</td>
<td>Initiator</td>
<td>Joy</td>
<td>43</td>
<td>&gt;$100k</td>
<td>College</td>
<td>Christian</td>
<td>19 months</td>
<td>Diminished Ovarian</td>
</tr>
</tbody>
</table>
Barriers and facilitators for treatment seeking and treatment initiation within the psychobiological, clinical, and sociocultural domains are discussed below. A comprehensive listing of themes are found in Tables 12 & 13 Themes were not reported if we found limited data that could be coded. The model quotes are presented with the participant’s pseudonym, age, and an identifier to show if the woman was an initiators (I) or a non-initiator (NI) of the recommended treatment plan.

### 4.3.2.1 Treatment Seeking

**Table 12: Psychobiological, Clinical, and Sociocultural Barriers and Facilitators to Treatment Seeking**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Barrier</th>
<th>Facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychobiological</td>
<td>a. This Didn’t Apply to Me: Low Risk Perceptions of Needing Infertility</td>
<td>a. Tired of Feeling This Way: Emotional Distress Prompting Self-Referral</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b. Failed First Line Treatment: Looking</td>
</tr>
</tbody>
</table>

| 4 | Non-Initiator Kathleen | 34 | >$100k G/P | Atheist | 8 months | Recurrent Miscarriages, Unexplained Reserve |
| 5 | Initiator Sylvia      | 39 | >$100k G/P | Christian | 36 months | Male Factor |
| 6 | Initiator Jerry      | 42 | >$100k G/P | Christian | 12 months | Male Factor |
| 7 | Non-Initiator CeCe  | 43 | >$100k G/P | Christian | 72 months | Diminished Ovarian Reserve |
| 8 | Non-Initiator Kiah  | 39 | >$100k G/P | Christian | 12 months | Secondary Infertility; Unexplained |
| 9 | Non-Initiator Hannah | 44 | >$100k G/P | Christian | 18 months | Unexplained Infertility |
| 10 | Non-Initiator Mary   | 32 | <$99k G/P  | Christian | 120 months | Unexplained Infertility |
| 11 | Initiator Ella       | 36 | >$100k G/P | Christian | 12 months | Diminished Ovarian Reserve |
| 12 | Non-Initiator Geechie | 40 | <$99k G/P  | Christian | 12 months | Fibroids |
| 13 | Non-Initiator Nae    | 39 | <$99k High School | Christian | 48 months | Unexplained Infertility |

106
Beyond Lifestyle Modifications

Clinical

a. Slipped Through the Cracks: Delayed Referral Despite Clinical Disclosure

a. It’s Complicated: Physician Referral Following Complex Gynecological Challenges

b. Will they get me? Seeking Providers with Culturally Diverse Clientele.

Sociocultural

a. I Wish I Would Have Known: Low Awareness of Treatment Options

a. Thank you, Michelle Obama: Social Media Influence on Peer Disclosure

b. Not Coffee Table Conversation: Delayed Peer Disclosure

There were several psychobiological, clinical, and sociocultural themes that emerged from the perspectives of all the participants as they reflected on what influenced them to seek treatment. These barriers and facilitators to treatment seeking are described below. Barriers and facilitators were grouped according to the psychobiological, clinical, and sociocultural domains.

Psychobiological Barrier. This Didn’t Apply to Me: Low Risk Perceptions of Needing Infertility Treatment. Despite many of the participants attempting to conceive for well over 12 months, many perceived having low risks for experiencing infertility which then delayed them from seeking treatment for their symptoms. They often attributed this low risk perception to their past medical histories and family histories that seemingly did not raise any concerns related to their experiences with attempting to
conceive. Participant, “Joy”, a 43 year old woman who sought and initiated treatment in her late 30s/early 40s described this when she stated:

I never thought I’d have any problems having kids, my mother has birthed six children and I come from a lot of very fertile people. But my mother had me at 19 so I never imagined having any problems. It was a surprise to me...Quite honestly, it wasn't on my radar as something that I needed to worry about. And I honestly didn't know it was going to be this important to me... I never thought of it as being my issue. (Joy, 43, I)

**Psychobiological Facilitator. Tired of Feeling This Way: Emotional Distress**

**Prompting Self-Referral.** Women who eventually sought treatment were often prompted with the emotional distress of not being able to conceive. Participant, “Geechie”, a 40-year-old woman experienced infertility for over a year prior to seeking treatment. She discusses how hearing a commercial advertisement for infertility services helped her understand that the root of her depressive symptoms were attributed to her inability to conceive over time.

...the months were just going by and I was like, this should be [easier]. I was like starting to feel bad. And I was like 'why is this not happening?’ And it was starting to get like say October, I'm like, somethings wrong…. It was more like something emotionally, like, like my emotional needs were not being met. The commercial made me conscious that I felt a certain way about the experience I was having with not being able to conceive and that prompted me to say let me go see why I’m feeling this way. It was more about a feeling because it was nothing in my mind that will make me think it was something physical. – Geechie, 40, NI.
Similarly, participant “Sylvia” a 39-year-old woman, pregnant at the time of the interview, waited three years before referring herself to the infertility facility. She discussed her and her husband experiencing unease with not being able to conceive.

….every time there was a period I would get sad. I was like oh my periods back again. Which is funny because when I was single. I was happy like, ‘yay I’m not pregnant!’ Once I got married, you know, I would be sad and even when my husband would find out….we’d both get sad. (Sylvia, 39, I.)

**Psychobiological Facilitator. Failed First Line Treatment: Looking Beyond**

**Lifestyle Modifications.** Participants discussed attempting to enhance conception by adopting new nutritional and lifestyle strategies. When these strategies did not help them achieve their family building goals, they eventually sought treatment. Participant, “Mary”, a 32-year-old women who waited 10 years prior to seeking formal evaluation for infertility details certain behaviors her and husband adopted to enhance chances of conceiving:

So the first seven years it was just kind of like hey let’s try to be more active, follow some of these apps, change our diet, increase our vitamins, you know stuff like that we were trying to do on our own. Year seven. I want to say for sure, your seven was right before we purchased our home was when we decided to talk to the doctors about it. (Mary, 32, NI)

**Clinical Barrier. Slipped Through the Cracks: Delayed Referral Despite Clinical Disclosure.** There were several women who discussed concerns with trying to conceive with their general practitioners. However, there were continued delays in
treatment seeking due to limited referrals to reproductive endocrinology and potentially inadequate clinical assessments. Utilizing the same participant, “Mary”, a 32-year-old woman who experienced infertility for “maybe like seven years in” prior to disclosing to her general practitioner. She stated she was not referred to a reproductive endocrinologist until “approximately about a year, about a year, maybe a little over a year, a year and a half.” Similarly, Participant “Sylvia” who experienced male factor infertility knew early on that her husband had survived childhood cancer and chemotherapy. She states that despite knowing early on his past medical history, they were not educated on the need for assisted reproductive technology to conceive.

My husband had cancer when he was a baby. Actually, before we got married, he told me I can’t have kids. He’s like, are you sure you want to marry me? And I’m like, did the doctor tell you that? He’s like, no. So I was like, how do you know you can’t have kids? I’m just sure I can’t have kids. So I didn’t believe him….. I said, OK, maybe it just takes a while… So I tried a lot of things and nothing was really working. So I felt that three years was a long time and something should have happened by now. So we went to the doctor [REI]. (Sylvia, 39, I).

Clinical Facilitator: It’s Complicated: Physician Referral Following Complex Gynecological Challenges. Women who sought treatment earlier often had previously occurring gynecological concerns that were being treated by surgeons or other women’s health providers. It was after receiving treatment for complicated gynecological issues that some of the participants were then educated by physicians that in order to conceive, they would need to use assisted reproductive technologies. Participant, “Meg”
described how complications with a previous pregnancy resulted in her needing emergent remove of key reproductive organs.

Well I never really tried to have a child. In one of my other marriages I had gotten pregnant and it was an ectopic pregnancy. So I had both of my tubes removed and I had like fibroid issues and cysts and things of that nature, where I had to have, uhm, an ovary removed. (Meg, 37, I)

Clinical Facilitator. Will they Get Me?: Seeking Providers with Culturally Diverse Clientele. Women expressed an importance in having providers who had culturally diverse clientele as they considered seeking treatment for their infertility concerns. Although clinical competence was valued, proven cultural competency as evidenced by positive reviews from diverse populations seemed to be regarded higher.

Participant, “Ella”, discussed her process of finding her reproductive endocrinologist. She used several search engines that specifically gave her details regarding the experiences of other Black women who sought care from providers in her local area:

I specifically researched… a profile of different plethora of different doctors. And I was able to, you know, research him heavily. Look at different reviews. And specifically, there’s a website called Fertility IQ and I was looking for doctors that had African-American patients… I literally was like, OK, which doctor had the most reviews from African-American, you know, patients?” (Ella, 36, I.)

Sociocultural Barrier. I Wish I Would Have Known: Low Awareness of Treatment Options. Many participants discussed delays in treatment seeking due to limited knowledge of infertility and the availability of treatment. Participant, “Ella”, a 36-year-old woman who found out that she had diminished ovarian quality after
exploring options for oocyte cryopreservation, stated that she believed her low awareness was due to a lack of comprehensive sexual education.

I feel like we were definitely educated about like HIV/AIDS, sex, STDs, but no one educates or takes the time to educate about fertility. All you’re suppose to know is that you are suppose to get your period every month. (Ella, 36, I.)

Further, participant “Nae” discussed how in her social surroundings, she never knew women who were offered treatment for issues related to conception.

In my neighborhood black women are the ones that get put on birth control because we the ones who having them, you know what I mean … I said I didn’t know anybody who went through a situation similar. I know people who had to get on birth control so they don’t get pregnant, like IUDs. Like this is the kinda stuff that, you know, I was exposed to that I knew about. I didn’t know anybody who needed assistance with getting pregnant. (Nae, 39, NI)

**Sociocultural Barrier. Not Coffee Table Conversation: Delayed Peer Disclosure.** Despite the emotional responses to not being able to conceive, participants discussed an initial delay of disclosure of infertility experiences to peer groups. Some described delaying disclosure in order to avoid any additional input from external sources, especially those who had limited knowledge of infertility.

This is not just coffee table conversation. I’m not opening myself up to other people’s energy surrounding the topic, their opinions, [and] their unsolicited advice. (Hannah, 44, NI)

Other women felt limited in the type of peer support they could experience after disclosure. Especially when not seeing other people in their peer groups who had
similar challenges than they did. Participant, “Kathleen”, 34-year-old women who was referred to the infertility clinic due to recurrent miscarriages shared how her inability to achieve a pregnancy to term isolated her from her peers that could not conceive.

…. a lot of my friends have been going through the same thing, which is also interesting. But for them, it was getting pregnant….Once they were able to get pregnant, everything was smooth sailing… I can’t be happy when I get pregnant because that’s not the issue. I have less people to talk to because most people it’s the other problem. So once they get pregnant they can be super happy. Versus I can’t be happy like until I actually have a baby. (Kathleen, 34, NI)

**Sociocultural Facilitator. Thank you, Michelle Obama: Social Media Influence on Peer Disclosure.** Women reported feeling encouraged to disclosure their status and subsequently seek treatment after a select group of celebrity and social media influencers disclosed their status. “Ella” described how learning about Michelle Obama and Gabrielle Union influenced her to finally to her sister and friends about her challenges. Once she and other participants opened up, many developed peer communities that provided emotional support, education, and even resources for financing procedures.

I think Michelle Obama was a big deal. In fact, we went to go see her speak and in fact after she had shared that in her book [it was then] that I felt comfortable sharing with my friends that, hey, actually, I’m going through through this. The Gabrielle Union thing. I remember listening to her podcast.. well she was on Oprah[s] podcast. And that was also very helpful from like the surrogacy thing and just, you know, what she went through. So I think those examples did add to one the visibility and two just comfort in terms of even me speaking about it,
because what I’m realizing is, is that it impacts a lot more folks, but we don’t talk about it a lot.

4.3.2.2 Treatment Initiation

There were several barriers and facilitators that influenced when and why Black women initiated the treatment plan for infertility. Barriers and facilitators were grouped according to the psychobiological, clinical, and sociocultural domains and discussed below. The themes are shown in Table 13.

Table 13: Psychobiological, Clinical, and Sociocultural Barriers and Facilitators to Treatment Initiation

<table>
<thead>
<tr>
<th>Domain</th>
<th>Barrier</th>
<th>Facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychobiological</td>
<td>a. Fighting Against the Odds: Choosing Personal Agency versus Biological Reality.</td>
<td>a. Now or Never: The Urgency of Age.</td>
</tr>
<tr>
<td></td>
<td>b. Accepting Failure: Treatment Avoidance Due to Infertility-Related Stress &amp; Stigma.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>b. I’m a Whole Person: Desiring Empathy &amp; Holistic Concern from the Healthcare Team.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>c. I Don’t Want to be a Statistic: Fearing Racial Discrimination in Clinical Care.</td>
<td></td>
</tr>
</tbody>
</table>
Psychobiological Barrier: Fighting Against the Odds: Choosing Personal Agency versus Biological Reality. After completing evaluation for infertility, some participants expressed resistance to starting treatment because they did not believe their current health status was cause for immediate concern. Participant, “Hannah”, a 44-year-old woman diagnosed with unexplained infertility after attempting to conceive for 18 months prior to seeking treatment, discussed not wanting to immediately start treatment and desired the opportunity to try on her own even for a short period of time against the advice of the reproductive endocrinologist. Ultimately, her decision to go with her personal preference differed from the biological facts that the physician wanted her to consider.

He then asked how old are you? And I told him, and then he asked if I had had unprotected sex, yes, and you’re not pregnant. And so, I was just like, okay, ….but I never actively tried. It’s not like I timed sex with ovulation because for the most part I avoided getting pregnant very successfully. But I did not, like, make an effort. Now I have an app on my phone, and it’s my first time getting it because now I’m really gonna try, but I never really tried. I never considered myself infertile, I just figured I hadn’t tried. But when they did the testing and saw that I had good egg reserves. And they’re like but every month it could change and I’m like well, everything was healthy and good, and I still didn’t really think that it was a problem, I mean I guess, but really, again. I’m still gonna have babies. (Hannah, 44, NI.)

Psychobiological Barrier. Accepting Failure: Treatment Avoidance Due to Infertility-Related Stress & Stigma. Participants who did not initiate treatment discussed prolong avoidance of treatment because of negative emotional responses to
their condition. The types of stigma that women discussed were label avoidance and self-stigma. Participant, “Kiah” described how she continued to contend with an emotional barrier that would not allow her to initiate the treatment plan.

...this sounds kind of rotten to say, but I keep thinking I know I’ve always kind of seen people who have had IVF in order to have a child. It does work that way because something was wrong... And part of my struggle is that I don’t want to feel like something is wrong with me, which is kind of a catch 22, because I kind of already feel that way. But it’s... getting over my own stigma in my head... [it would be] like accepting failure. That my body couldn’t do it on its own or that there was something wrong with me. (Kiah, 39, NI).

Psychobiological Facilitators. Now or Never: The Urgency of Age. Although some non-initiators may have not wanted to fully consider their advancing age as an influential aspect to when they initiated treatment, participants in the initiator group seemed to base some of their treatment actions based on the realities of age and treatment success. Participant, “Sylvia”, when asked what advice she would give to another woman considering treatment stated:

I feel like as the age goes up, the likelihood of you conceiving get smaller decreases. So I would say, if you’re going to do something you should do it now. And don’t assume it’s going to happen on its own. (Sylvia, 39, I).

While “Jerry” talk about her provider emphasizing the need to act expeditiously because of her advancing age.

I think what the main agenda they kind of push is that you have to do something now. You know, your clock is ticking. So, you know, that was the message that I
got. It’s like you’re getting old you’re getting old, something I kind of already knew. (Jerry, 42, I)

Clinical Barriers: Concerns for Treatment Plan: Complexity & Applicability.

After participants learned about the recommended treatment plan, participants who did not initiate treatment expressed concerns with the complexity of the treatment plans. Participant, “Kiah”, who was recommended to do in vitro fertilization discussed hesitancy because of the treatment protocol that required self-injections and an egg retrieval.

I don’t know how painful egg retrieval is but it sounds like it’s unpleasant. And I have seen many of stories and sometimes even pictures on television shows where the women are getting shots and things like that. None of that really appeals to me, it kind of break my heart. And it also gives me a lot of it gives me pause when deciding whether or not there’s something I want to go through. (Kiah, 39, NI.)

However, some participants discussed concerns with the treatment plan because of not understanding how it was relevant or useful for their type of diagnosis. “Kathleen”, who experienced recurrent miscarriage felt like her plan of in vitro fertilization was not aligned with the type of treatment she felt she required.

I think we were a little unsatisfied, not with the doctor per say, but just because I think a lot of [the clinic] revolves around you not being able to get pregnant at all. And so for us, I think our frustration was…the plan is sort of nebulous because we don’t have that issue. We have the issue of staying pregnant. So were like, “OK, you know, do the best that we can with this plan, but it doesn’t feel like it applies.” (Kathleen, 34, NI)
Clinical Barriers. I’m a Whole Person: Desiring Empathy & Holistic Concern from the Healthcare Team. Several participants noted that the provider interactions reduced their desires to continue with the recommended treatment plan. Participant, “Nae”, who was advised to lose weight before any additional treatment could be considered, stated she felt like the provider lacked empathy in his delivery and seemed to not acknowledge the severity of her concerns.

I cried, uhm, yeah so I mean....this is a sensitive subject. So when you when you talking to a doctor who that’s all he sees all day long, your situation doesn’t seem too much different from everybody else’s situation. But when you’re that patient, your situation seems so dire. So of course like. I don’t know if I wanted him to hug me or what, you know what I mean? I don’t know what I was expecting. But long story short, he basically told me that I was too fat to do IVF and I needed to lose weight and come back and that’s how that went. (Nae, 39, NI)

After her experiences with the provider, “Nae” ultimately completed a first round of treatment at another fertility clinic in her local area within 3 months. Further, participant “Geechie”, a 40 year old woman who was advised to have surgery to remove fibroids prior to treatment expressed concerns with how she was advised on the long term consequences of the surgery.

Its like, I understanding that I need to do this for as far as my own perspective to have a child but I’m not going to make a decision that I don’t feel is connected to my wellbeing. I don’t care if it is something on a timeline, because ya age is looking a certain way, if I’m not well, whatever comes through me is not well. That’s why I haven’t gone back, because I just felt like it just wasn’t directly connected to my wellness, like beyond the baby, beyond the goal. (Geechie, 40, NI).
Clinical Barriers. I Don’t want to be a Statistic: Fearing Discrimination in Clinical Care. Participants who did not initiate the treatment discussed concerns with the short and long term safety of initiating treatment. Participant, “Hannah”, who was recommended in vitro fertilization discussed wanting a team of providers at the reproductive endocrinology office and her obstetrics team to be aware of her safety concerns as a Black woman in the age of increased attention to Black maternal mortality. She describes her experience of wanting providers who will listen to her and not dismiss her during critical moments in her treatment.

…I need to pick up something about their attitude towards black women... I looked at his walls, a picture of the baby that he delivered both of them White...That says nothing about his politics or ideas or his beliefs. But it may tell me something about how he might communicate with me as a considerably younger, than he is, black woman. And so yeah that definitely concerns me, concerns me a lot....And, you know, not just because of IVF or (fertility clinic), but just because I need to feel confident that I have competent health care providers. (Hannah, 44, NI)

Clinical Facilitators. A Well-Oiled Machine: Clear Understandings of Treatment Plan and Processes. Women in the initiator group expressed having a clear understanding of the treatment plans and what was required of the process. Participants “Beyonce” and “Jerry” both expressed how they were educated on the treatment plan and seemed to trust the approach the physicians, nurses, and other ancillary staff maintained.
It's like a well-oiled machine. They have a routine, and they know what they're doing. They know what they're talking about and if you follow what they say it tends to work out. (Beyonce, 36, I)

The physician drew diagrams, and you know, explained where we would go in the time frame and everything, so at that point we felt pretty, pretty happy with the way things were going. (Jerry, 42, I).

**Sociocultural Barriers. A La Carte Coverage: Limited Benefits from State Mandates.**

Although women were recruited from an infertility clinic in a state with insurance mandates to cover at least 3 rounds of invitro fertilization, participants described experiencing setbacks in initiating treatment because of the lack of comprehensive coverage even in the presence of insurance. Participants, “Kathleen” and “Mary” discuss having to delay treatment because of the need to have to garner additional resources in order to start treatment. “Kathleen” eventually started treatment after securing a loan.

So my insurance only covers....certain aspects of [infertility clinic]. So if I go there to do like an OB/GYN appointment, like a routine appointment, that’s covered at the same rate as like me going to see anybody would be covered. But the actual [treatment] itself is not covered. So we actually had to take out a loan in order to pay for that. There are other things like the anesthesiology or whatever. So my insurance paid for part of that because it’s anesthesiology for a particular kind of surgery that’s covered under my insurance. Medication? Absolutely not that’s out of pocket. (Kathleen, 34, NI)

Zero dollars for infertility coverage. That made a major difference, especially with me being an independent contractor working for myself. Of course, you know, I'm only on his. So we hit that bump and found out that there was like grant scholarships and things that we could go out for, which found out at least for the
fall round it was too late to try to go out for it right now. So, it’s on our list of things to try to do for the spring to go out for one of those grants to help pay for it. (Mary, 32, NI)

**Sociocultural Barriers. It Takes Two: Desires for Family Building, Previous Paternity, and Limited Partner Support.** Women who did not initiate treatment had partners who did complete evaluation with them. However, women in the non-initiator group experienced more partner resistance, ambivalence towards treatment, and considered not initiating treatment due to partner’s maturity level and previous paternity. “CeCe” discussed why she ultimately decided not to initiate treatment because of her partner.

Based on my relationship, I was like, we’re not doing that. *laughter*. The money was a part of it, but I probably would have been able to work it out if the relationship was real stable because my partner has the little children prior and I saw his parenting style was very much in conflict with mine...I don’t want to bring a child into this factor because then I’m still gonna be like a single parent now, and I didn’t want that. And so to me, it was more important to have the family than the child... And so I’ve also realized my partner, he said initially going in he was, he wanted to have a baby, but then it came out later. No, I really don’t want that, I don’t want any more children. So after three years in a relationship, you just now decided to come clean because I’m asking you?… and that was the deal breaker for me. (Cece, 43, NI).

**Sociocultural Barriers. God’s Plan: Tensions with Faith.** Participants who did not initiate treatment often described how their faith provided some conflict as they considered whether or not to initiate treatment. “Kiah”, who was experiencing
secondary infertility, who discussed how her faith has caused her to question whether she should initiate treatment.

I was raised with the belief that, you know, God does what God will do in God’s time. And sometimes when you ask God for things the answer is no. And we need to learn to accept the answer and not lean into what we want the answer to be… if we can’t get pregnant naturally, then maybe that’s God’s way of saying no. And if I am using science as a run around that then I am going against God’s will. Maybe there’s a reason that he won’t. He doesn’t want me to have another child. (Kiah, 39, NI).

Sociocultural Facilitators. By Any Means Necessary: Financial Ingenuity in the Face of Uncertainty. For women who initiated treatment within 3 months, they too experienced financial challenges even with insurance coverage. Participant, “Sylvia”, talked about how having insurance coverage helped with her in vitro fertilization, however, she did experience some out of pocket costs for treatment.

They did a very good job with the treatment. It was only six hundred dollars, so I was excited about that. But there was a catch we had to pay for all the medication and that was thirty two hundred dollars. (Sylvia, 39, I)

Many participants discussed the additional burdens associated with unexpected treatment fees. However, participants discussed that their desire for parenthood fueled them to look at alternative options for payment. These included applying for loans, grants, picking up additional shifts at work, or exploring other work options to obtain more comprehensive coverage. “Jerry”, describes how her and husband considered their
finances to cover parts of treatment that insurance did not.

I mean… [we’re] trying to figure it, figure out how to get it within a budget. But again, you know, we’ve always known we wanted a family, so this seemed like the best way to go about it. So, you know, we just have to figure out how. We always knew that we’ve always wanted to. We just had to figure out how to make it happen. (Jerry, 42, I.)

**Sociocultural Facilitator. It Takes Two: Valuing Partner Support in Decision Making.**

Participants who initiated treatment described that their partners played a large role in that decision. Participants described having partners who were participated in treatment plans, emotionally supportive, and equally valued parenthood at the time of treatment. Women also described valuing joint decision making in the process.

He was as invested in our family and as I was I believe. And he provided all, you know, all the emotional support, especially in that, during that first cycle when nobody really knew about it besides the two of us. So really just he played the role of, you know, of the support. And, you know, if I ever needed to bounce ideas off, you know, then he, he was my sounding board. (Jerry, 42, I)

The hits kept coming with the treatment and there’s so many needles, he was the one giving me the shot…I had gotten to the point where I was like, we’re not making any decisions that we’re not in agreement about. (Joy, 43, I.)

**God’s Plan: Acceptance with Faith.** For women who initiated treatment, faith influenced how they viewed their treatment options. Although many would self-describe as “not super devout”, there were several participants who shared that their faith propelled them to initiating treatment.
I’m speaking as a faithful Christian women... Lean on the faith of God, because that’s all I have going through or preparing to go through this process….I feel driven and I feel as though God has revealed this path to me and the outcome is unknown. However, I feel confident that God is walking with me through this process. (Ella, 36, I.)

Sociocultural Facilitators. Educational Advantages: Exposure and Personal Agency. Although many women were highly educated, many rejected the idea that their educational degrees and titles played direct roles in them initiating the treatment plan. Participants often described the benefits of having higher education that allowed them to gain exposure to new geographic areas, technology, resources, and peer groups that helped them consider what treatment options worked best for their individual needs.

Participants, “Sylvia” and “Joy” described this:

I don’t think my masters taught me that. But maybe just having like its just overall, real holistic view of life, I guess? I don’t know how to explain that. Yeah. Because I feel like they’re certain people stay in certain areas and never leave. So they don’t have a well-rounded view of life. (Sylvia, 39, I).

Not because I’m so smart, but because I think not just education but geographic area because I live in a metropolis area and have access to things like this. Uhm… Yeah, I think that that may have played a part. Maybe if I lived in Timbuktu town, you know, nowhere. Maybe I wouldn’t have known as much about it. I can assure you my grandmother has never heard of IVF. (Joy, 44, I)

Additionally, even participants with less formal education did attribute their instinctual desire for more information as a driving factor when considering whether or not to initiate treatment. “Meg”, who completed an associate’s degree was given the
treatment option of in vitro fertilization. She stated that she was not one to always rely on the physician’s recommendations, but rather, her educational background in conjunction with her personal agency is what influenced her to initiate treatment.

I’m not sure about [that] because I always did research. Like I never just take anything someone tells me straightforward. Like I wanna know why. And as you know the doctors and professionals, they will tell you but you still don’t know why. And you know they will think that they’re the professionals and not explain in detail so I would find myself doing a lot of my own research. Just to make sure what they were saying was right and if I felt like something wasn’t right, you know then I would absolutely question it. I want to know why. Like it wasn’t like someone said, you know, do this. I’m just like okay, I want to know why and is there any other alternative. (Meg, 37, I)
4.3.3 Integration

4.3.3.1 Treatment Seeking

The themes emerging from the qualitative findings were compared and merged with the quantitative characteristics of the study sample of all the Black women who sought treatment for infertility. The comparison and merging of the data resulted in convergent, divergent, expanded, and emergent findings. The joint data display of the psychobiological, clinical, and sociocultural description of Black women who sought treatment for infertility is found in Table 14.

Table 14: Joint Data Display for Psychobiological, Clinical, and Sociocultural Characteristics of Black Women Who Seek Treatment

<table>
<thead>
<tr>
<th></th>
<th>Quantitative</th>
<th>Qualitative</th>
<th>Mixed Methods Analysis &amp; Integration</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Psychobiological</strong></td>
<td>*The mean age when women sought treatment was 35.5 +/- 4.8 years old.</td>
<td><strong>This Didn’t Apply to Me:</strong> <strong>Low Risk Perceptions of Needing Infertility Treatment.</strong> I never thought I’d have any problems having kids, my mother has birthed six children and I come from a lot of very fertile people. But my mother had me at</td>
<td>Expansion – the quantitative data and the qualitative data align. The qualitative data expands our understanding of why Black women wait longer to seek treatment. Bl</td>
</tr>
</tbody>
</table>
so I never imagined having any problems. It was a surprise to me...Quite honestly, it wasn’t on my radar as something that I needed to worry about. And I honestly didn’t know it was going to be this important to me... I never thought of it as being my issue. (Joy, 43, I)

infertility are often older, experience infertility for significantly longer time than the treatment guidelines and have lower perceptions of their risk for infertility.

55 (14.2%) 1 or more comorbidity. Further, less than 2% of the population had an Anxiety or Depression diagnosis respectively.

*Overweight or obese with body mass index scores of 25 kg/m² or higher (63.5%).

*Median time experiencing infertility in months: 24 (12, 36).

*Tired of Feeling This Way: Emotional Distress Prompting Self-Referral
....every time there was a period I would get sad. I was like oh my periods back again. Which is funny because when I was single. I was happy like, ‘yay I’m not pregnant!’ Once I got married, you know, I would be sad and even when my husband would find out....we’d both get sad. (Sylvia, 39, I)

Failed First Line Treatment: Looking Beyond Lifestyle Modifications. So the first seven years it was just kind of like hey let’s try to be more active, follow some of these apps, change our diet, increase our vitamins, you know stuff like that we were trying to do on our own. Year seven. I want to say for sure, your seven was right before we purchased our home was when we decided to talk to the doctors about it. (Mary, 32, NI)

Divergence – the quantitative data does not align with the qualitative data.

Black women who seek treatment often experienced high levels of fertility related psychological disturbances, however, they were least likely to have documented psychological disorders.

Emergence & Expansion – the qualitative data expanded on the quantitative data.

Black women who sought treatment were more likely to be overweight, despite previous attempts at adopting lifestyle modifications. Black women who attempt their own interventions may experience longer time periods to seeking treatment.
*Of the women who sought treatment (N=391) they were more likely to experience Fibroids (30.2%) and tubal disorders (36.3%). 39.9% had one or more gynecological disorder.

It's Complicated: Physician Referral Following Complex Gynecological Challenges. Well I never really tried to have a child. In one of my other marriages I had gotten pregnant and it was an ectopic pregnancy. So I had both of my tubes removed and I had like fibroid issues and cysts and things of that nature, where I had to have, uhm, an ovary removed. (Meg, 37, I)

*Median time experiencing infertility in months: 24 (12, 36)

Slipped Through the Cracks: Delayed Referral Despite Clinical Disclosure. My husband had cancer when he was a baby. Actually, before we got married, he told me I can’t have kids. He’s like, are you sure you want to marry me? And I’m like, did the doctor tell you that? He’s like, no. So I was like, how do you know you can’t have kids? I’m just sure I can’t have kids. So I didn’t believe him..... (Sylvia, 39, I).

Convergence – the qualitative data aligns with the quantitative data.

Black women who sought treatment experienced multiple gynecological diagnoses when they sought treatment.

Expansion – qualitative data provides additional information on the quantitative data.

75.2% of women who sought treatment had qualifying insurance for infertility.

*I Wish I Would Have Known: Low Awareness of Treatment Options. In my neighborhood black women are the ones that get put on birth control because we the ones who having them, you know what I mean ... I said I didn’t know anybody who went through a situation similar. I know people who

Divergence – The quantitative data does not align with the qualitative data.

Black women who seek treatment are often not aware of the treatment options available to them, despite having qualifying insurance.
had to get on birth control so they don’t get pregnant, like IUDs. Like this is the kinda stuff that, you know, I was exposed to that I knew about. I didn’t know anybody who needed assistance with getting pregnant. (Nae, 39, NL)

*Not Coffee Table Conversation: Delayed Peer Disclosure*

This is not just coffee table conversation. I’m not opening myself up to other people’s energy surrounding the topic, their opinions, [and] their unsolicited advice. (Hannah, 44, NI)

Emergent – there was no quantitative data that supported the qualitative data.

Black women experienced limited social support when they sought treatment due to limited disclosure to social circles.
The quantitative findings showed that Black women who sought evaluation and initiated treatment were often older, had qualifying insurance, and waited two years to seek treatment for infertility. The women also had several gynecological diagnoses upon evaluation for infertility. Qualitative findings were concordant and explained many of the barriers and facilitators to treatment seeking that may have led to these delays in reproductive evaluation. When merging these findings, we understood that Black women who sought treatment for infertility are often older, experience infertility for significantly long amounts of time with infertility because they have lower perceptions of their risk for infertility, lower understanding of treatment options, and were often referred by their general practitioners only when they have complex gynecological conditions. The low awareness of treatment options was inconsistent with the quantitative findings because women in this study were more likely to have qualifying insurance with infertility benefits. Further, qualitative findings suggest that women will often seek treatment as a result of negative psychological and emotional reactions to not being able to conceive. This contrasted the quantitative findings that showed less than 5% of the sample reported diagnoses of depression or anxiety.
4.3.3.2 Treatment Initiation

The themes emerging from the qualitative findings were compared and merged with the quantitative findings that examined influences on treatment initiation. The comparison and merging of the data resulted in convergent, divergent, expanded, and emergent findings. The joint data display of the psychobiological, clinical, and sociocultural influences on initiation among Black women is found in Table 15.

Table 15: Joint Data Display for Psychobiological, Clinical, and Sociocultural Influences on Treatment Initiation

<table>
<thead>
<tr>
<th>Quantitative Predictive</th>
<th>Qualitative</th>
<th>Integration Analysis &amp; Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>*BV - Qualifying Insurance (p.0029, OR 2.100, 1.288, 3.424). Odds of initiating treatment are 2.1x higher in women with qualifying insurance in those who do not have qualifying insurance.</td>
<td>By Any Means Necessary: Financial Ingenuity in the Face of Uncertainty They (insurance company) did a very good job with the treatment. It was only six hundred dollars, so I was excited about that. But there was a catch we had to pay for all the medication and that was thirty two hundred dollars. (Sylvia, 39, I)</td>
<td>Expansion - The qualitative data supports and expands the quantitative data regarding the association of having qualified insurance to treatment initiation. Although women who had qualifying insurance experienced less barriers to initiation than women who did not, they were still met with additional fees for treatment that required the allocation of supplementary resources.</td>
</tr>
<tr>
<td>*LR - Qualifying Insurance (aOR = 1.977, 95% CI: 1.196, 3.268). Odds of initiating treatment are 2.0x higher in women with qualifying insurance than those who do not have qualifying insurance.</td>
<td>A La Carte Coverage: Limited Benefits from State Mandates. Zero dollars for infertility coverage. That made a major difference, especially with me being an independent contractor working for myself. Of course, you know, I’m only on his. So we hit that bump and found out that there was like grant scholarships and things that we could go out for, which found out at least for the fall round it was too late to try to go out for it right now. So, it’s on our list</td>
<td></td>
</tr>
</tbody>
</table>
Concerns for Treatment Plan: Complexity & Applicability.

I don’t know how painful egg retrieval is but it sounds like it’s unpleasant. And I have seen many of stories and sometimes even pictures on television shows where the women are getting shots and things like that. None of that really appeals to me, it kind of break my heart. And it also gives me a lot of it gives me pause when deciding whether or not there’s something I want to go through. (Kiah, 39, NL)

The qualitative data does not support some of the non-significant quantitative data regarding the treatment complexity and applicability.

Divergence - Women make considerations of the complexity and invasiveness of treatment as they decide whether or not initiate treatment.

Emergence – The qualitative data suggest that’s the level of agreement on the applicability of the treatment plan may influence initiation. Additional information from the quantitative data that highlighted the degree of treatment agreement/acceptance would have been helpful.

*BV - Combination oral & Injection Medications. (p = 0.1771, OR 0.557, CL 0.238, 1.303). Odds of initiating treatment were 79.5% higher in woman that did not have a combination medication regimen than those who had combination medication

*BV – Oral Medication Only (p = 0.4441, OR 1.645, CI 0.460, 5.891). Odds of initiating treatment were 64.5% higher in women who had only oral medication than those who did not have just oral medication

*BV – In vitro fertilization (p = 0.4791, OR 0.822, CI 0.478, 1.414)
Odd of initiating treatment were 21.7% higher in women who did not have IVF as their treatment plan than those who had IVF as their treatment plan.

*BV – Age (p = 0.7218, OR 1.009, CI 0.963, 1.057) The odds of initiating treatment were similar in women who were younger in age and women who were older.

Descriptive Statistics – Mean Age

of things to try to do for the spring to go out for one of those grants to help pay for it. (Mary, 32, NI)

The quantitative data not support the non-significant quantitative data regarding the treatment complexity and applicability.

Emergence – there was a mixed effect of advanced aging on whether participants initiated treatment or not. Some women discussed feeling an urgency, while others did
35.5 ± 4.8

*Fighting Against the Odds: Choosing Personal Agency versus Biological Reality.*
He then asked how old are you? And I told him, and then he asked if I had had unprotected sex, yes, and you’re not pregnant. And so, I was just like, okay, …but I never actively tried. It’s not like I timed sex with ovulation because for the most part I avoided getting pregnant very successfully. But I did not, like, make an effort. Now I have an app on my phone, and it’s my first time getting it because now I’m really gonna try, but I never really tried. I never considered myself infertile, I just figured I hadn’t tried.

*Qualitative Significant (no relevant data)*

A Well-Oiled Machine: Clear Understandings of Treatment Plan and Processes.
It’s like a well-oiled machine. They have a routine, and they know what they’re doing. They know what they’re talking about and if you follow what they say it tends to work out. (Beyonce, 36, I)

There was no relevant quantitative data to support the qualitative data.

Emergence - High understanding of the clinical treatment plan influenced initiation.

*It Takes Two.*
I had gotten to the point where I was like, we’re not making any decisions that we’re not in agreement about. (Joy, 43, I)

The qualitative data expanded on the partnered status of women in the quantitative sample.

Expansion – The role of the partner when considering when to initiate treatment has a considerable effect.

*God’s Plan: Tensions with Faith.*
I was raised with the belief that, you know, God does what God will do in God’s time. And sometimes when you ask God for things the answer is no. And we need to learn to accept the answer and not lean not consider their age but rather the findings of their clinical assessment.

*Expansion – Findings suggest that faith plays a complex role when women are considering
into what we want the answer to be... if we can't get pregnant naturally, then maybe that's God's way of saying no.

*God’s Plan: Acceptance with Faith.
I’m speaking as a faithful Christian woman... Lean on the faith of God, because that’s all I have going through or preparing to go through this process....I feel driven and I feel as though God has revealed this path to me and the outcome is unknown. However, I feel confident that God is walking with me through this process. (Ella, 36, I.)

Accepting Failure: Treatment Avoidance Due to Infertility-Related Stress & Stigma.
...this sounds kind of rotten to say, but I keep thinking I know I’ve always kind of seen people who have had IVF in order to have a child. It does work that way because something was wrong... And part of my struggle is that I don’t want to feel like something is wrong with me, which is kind of a catch 22, because I kind of already feel that way. But it's...getting over my own stigma in my head... [it would be] like accepting failure. That my body couldn’t do it on its own or that there was something wrong with me. (Kiah, 39, NI).

The quantitative data did not support the qualitative data.

Divergence – women experienced a myriad of psychological and emotional challenges as they considered whether to initiate treatment.

BV - Women who had no past medical diagnoses, had a non-significant 8.7% increased odds of initiating treatment. (p = 0.7963, OR 0.920, CI 0.490, 1.728).
In the quantitative data, women were shown to have higher odds of initiating treatment if they had qualifying insurance. The qualitative findings supported and expanded our understanding of the role insurance when women considered initiating treatment. Although women who had qualifying insurance experienced less barriers to initiation than women who did not, they were still met with additional fees for treatment that required the allocation of supplementary resources.

Some of the non-significant quantitative findings were supported by qualitative findings in this study, such as the influence of age on treatment initiation. The qualitative data expanded on this showing that non-significant influence on treatment initiation could be due to mixed perceptions of biological age influencing the need to act urgently or prudently. Further, among all the recommended treatment plans and the medication regiment plans, none of the clinical factors in the quantitative arm were shown to influence treatment initiation at the bivariate or logistic levels. However, the qualitative findings suggested that women were influenced by how well they understood the recommended treatment plan and perceptions of invasiveness did play a role.

It is important to note that provider comfort was an emergent finding from the qualitative portion and could not be compared to any data in the quantitative portion. Actual providers and their success rates were not collected. However, it is important to
note that the level of physician cultural and clinical competence were influential factors in the seeking of treatment where women sought care from physicians who not only had high success rates, but high favorability among a diverse group of patients. Similarly, the role of the partner when considering when to initiate treatment had a considerable effect, however, there was no supportive data beyond the fact that they were partnered to help understand this influence. Further, complimentary quantitative data to help expand our understanding of social support, religious values, and stigma on treatment initiation were not available.

4.4 Discussion

This study sought to provide a comprehensive multidimensional description and conceptualization of Black women’s experiences with seeking and initiating treatment for infertility. Along the psychobiological, clinical, and sociocultural domains, there were several areas where qualitative and quantitative findings converged, diverged, and new findings emerged. Consistent with many studies that describe patient characteristics in treatment utilization for infertility, insurance coverage remains a salient factor for initiating concerns based on the quantitative findings of this study. Despite living and seeking treatment in a state with infertility insurance mandates, previous literature has shown that spending remained higher for women with insurance because of varying levels of coverage offered by employers or private insurance
companies (Boulet et al., 2019). This lack of comprehensive coverage leading to supplementary out of pocket expenses has also been known to influence the extent of fertility decision making even in a group of women in Canada where there is comprehensive coverage for some types of infertility treatment (Jones et al., 2012). Also, gender inequities in coverage have led to couples with male factor infertility not having comprehensive access to treatment in 8 states with insurance mandates (Dupree et al., 2018).

Although extensive descriptions of the relational status of the women were not collected and included in the analysis, the inclusion criteria of the study required that all women be in partnered heterosexual relationships at the first visit. Findings within the qualitative arm emerged with evidence that partnered decision making played a large role in decisions where men who expressed equal commitment to treatment and parenting tended to influence their partners to initiate treatment. These findings align with Duthie et al. (2017) who found that different family-building priorities between the male and female partner influence the type of treatment couples prefer with regard to infertility treatment. Other studies have explored the extent to which length of cohabitation, partner’s fertility related stress, and perceived support from partner has influenced the degree of treatment use (Johnson & Johnson, 2009; Martins et al., 2014). Many women within this study who initiated treatment expressed strong resistance
towards the idea of sole-autonomous decision making in this process and valued the input of their partners. This finding supports the complex nature of decision making which adds to the body of literature that positions couples’ joint decision-making as an extension of autonomous decision making and is the result of racial, ethnic, religious, and other cultural practices (Osamor & Grady, 2018).

The literature has shown the racial concordance between patient and provider has been known to increase trust and higher perceived quality of decision making (Martinez et al., 2016). Reproductive endocrinologists are trained as obstetrician-gynecologists with advanced education, research, and professional skills in endocrinology and infertility (Barnhart et al., 2015). Estimates show that of the 1,100 certified reproductive endocrinologists, only 3% are African American (Barnhart et al., 2015). For this study, it was important to note that there were no African American reproductive endocrinologists in this clinical setting where these women sought treatment. Therefore, patients sought physicians who were known to have a compatible communication style that was patient-centered and culturally congruent. This practitioner preference is consistent with studies that show effective communication can positively influence decision making among minority groups, especially in settings with limited minority practitioners (Saha & Beach, 2020).
It is also important to note how many of the psychobiological factors such as age, amount of time experiencing infertility, and past medical history were not significantly associated with treatment initiation, but there were mixed associations among women interviewed. Many women felt their age was an important aspect of treatment decisions however some were resistant to the idea of starting treatment solely on the basis of age. This is important to note because treatment efficacy is known to decrease with age (American Society of Reproductive Medicine, 2020). This idea that waiting would not be harmful to treatment outcomes could be explained by religious beliefs playing a larger role on treatment decisions. Religious beliefs, especially those rooted in the Christian context, have been known to be barriers and facilitators as women negotiate their moral stance on treatments for infertility (Klitzman, 2018). Further, the qualitative portion highlighted a need for further exploration of the psychological and emotional status of Black women who seek treatment for infertility. Less than 5% of the population had diagnosed anxiety or depression however, symptoms related to prolonged sadness and irregular emotions were highly evident when women discussed the impact of infertility. It is well established that infertility is often accompanied by severe psychological effects including anxiety, depression, and social isolation (Bai et al., 2019). Although women did report social isolation by way of delaying disclosure of their fertility status to their
peers, the findings suggest that Black women’s psychological and social concerns are not being identified nor addressed.

4.4.1 Limitations

Though limitations were present, there were several strengths of the mixed methods approach. There was a clearer understanding of the barriers and facilitators to treatment, especially as information from the interviews helped provide more insight of some non-statistically significant variables. The qualitative portion of data contained a diverse sample of women of varying ages, treatment stages, and infertility types. However, generalizability is limited due to this study only examining Black women in one geographical location. Due to the complexity of decision making and the limited data availability within the electronic medical record, some aspects of the data could not be compared or integrated. However, rigorous adherence to data abstraction protocol and the trustworthiness of the qualitative data remained high. Finally, due to the complexity of decision making and the limited data availability within the electronic medical record, some aspects of the data could not be compared or integrated.

4.4.2 Future Directions

To the best of our knowledge, this is the first study of its kind to explore the experiences of treatment seeking and influences of treatment initiation for infertility among a sample of Black women. Methodologically, this is also the first study to
incorporate mixed methods approaches in this population. The findings of this study highlighted a great need for future interventions for decision making for individuals and couples who are most vulnerable to disparities in reproductive endocrinology utilization. Clinical practice especially within women’s health should focus on enhancing education on infertility risk, treatment options, and long-term consequences of treatment delay. Policy changes should be considered to include more comprehensive coverage for infertility or at least modified to reduce the stratification of reproductive endocrinology services and reduce the need for supplementary resources.
5. Conclusions

The purpose of this dissertation was to provide a better understanding of the barriers and facilitators to treatment seeking, treatment initiation, and treatment completion for Black women experiencing infertility. This body of work addressed major gaps in the scientific literature that failed to describe the treatment seeking process among diverse groups of women who struggle to build families. The current scientific literature within reproductive endocrinology has often reported the experiences of Non-Hispanic White women therefore findings were never generalizable for Black women who struggle with infertility.

Guided by Chrisman’s Health Seeking Process, this dissertation provided insight of the multi-dimensional influences that shape the experiences of Black women as they address their inability to achieve conception or carry a pregnancy to term. The dissertation lays a strong foundation for factors that influence reproductive endocrinology health disparities affecting Black women in the United States. Further, the main dissertation study showed that mixed methods designs and approaches are well-suited to provide comprehensive and informative knowledge regarding the experiences of marginalized groups in reproductive endocrinology. In this section, we provide a comprehensive discussion of the multidimensionality of the treatment experience for Black women through each stage of the treatment experience.
5.1 Treatment Seeking

The overall findings from the dissertation showed that Black women experienced many psychobiological, clinical, and sociocultural barriers when beginning their journey with finding solutions for their infertility. Despite the Black women in Chapter 3 and Chapter 4 being highly educated, employed, partnered, and from higher socioeconomic groups, they proved to remain vulnerable to the similar barriers found in the systematic review findings from Chapter 2 of Black women from lower income groups. Chapter 2 provided a strong foundation to describing the state of the science that detailed barriers and facilitators to treatment seeking for all women in the U.S. In the analysis, Chapter 2 showed that common barriers to early stage treatment seeking for infertility were internalized stigma, having access limited by professional careers, and low or no social support supporting treatment seeking, and negative perceptions of the clinical environment. However, many of those barriers were discussed in studies that had majority samples that were ethnic minorities from low resourced areas (Nachtigall, 2009; Bell, 2014; Ceballo et al., 2015; Bell, 2016; Bell, 2017). However, the women in Chapter 3 and 4 study samples did not face challenges in accessibility for infertility treatment. The women in our study were situated in a region with insurance mandates and this specific fertility clinic provided their patients access to over a dozen satellite locations to manage their needs. Nevertheless, these women faced additional barriers to treatment evaluation
due to health-related stigma and poor clinical management that hindered them from seeking care for their fertility concerns. Further, despite women in the large retrospective sample having lower reported past, current, or lifetime diagnosis with depression and anxiety, the qualitative data revealed that these comorbidities are undetected and underreported in Black women. This may show that Black women are not being appropriately screened for mental health disorders. Further, this study highlights other areas where Black women are not being adequately screened and there are missed opportunities to teaching, early identification, or early intervention. For example, Black women should be screened yearly to assess for their desires of biological parenthood. This early identification of infertility could prevent younger and older from waiting well beyond the clinical guidelines for infertility diagnosis. Delays in treatment and clinical interventions are known to lead to more advanced treatment options that are more costly and complex in nature.

However, women in Chapter 4, specifically those who initiated treatment discussed several positive attributes to their treatment experiences. Like the facilitators reported in Chapter 2, Black women who initiated treatment evaluation experienced high desire for parenthood especially when their partners also agreed, had sources of social support encouraging treatment, and advanced health literacy. As the factors that facilitating converge between those two chapters, it could suggest that positive social
and cultural ideologies surrounding infertility and treatment can act as protective factors to treatment seeking and should be further explored.

5.2 Treatment Initiation

As Black women moved beyond the early phase of the treatment process, there were additional barriers and facilitators that influenced decisions to initiate the recommended treatment plan. After the clinical assessment, the majority of the women in the quantitative and qualitative arms were recommended the most invasive and expensive form of assisted reproductive technologies, in vitro fertilization. Not many women in Chapter 4 reported barriers to initiation related to the invasiveness of the procedure itself. However, many of the women discussed desiring not only clinically competent providers, but culturally sensitive and patient-center care. The quantitative findings showed that the women who possessed qualifying insurance had higher odds of treatment initiation. Though reported as a significant aspect of infertility treatment initiation decisions, many of the women qualitatively reported additional barriers in the form of significant out of pocket costs for medications to even begin the recommended treatment plan. Though located in a state with active insurance mandates, the current policy for the region did not provide comprehensive treatment coverage and many stipulations for employment or personal residencies limited the accessibility of those benefits.
It would be important to not underscore the value that many women placed on partnered decision making. Further, attributes of the partnership were also important as women considered whether or not to initiate treatment. Further research should examine the characteristics of partners and understand if the status of the partnership influences treatment. For example, studies that measure marital satisfaction, congruent desires for parenting, or health status of partners should be explored. Further, in the qualitative findings, many participants discussed contending with the previous paternity of their partners. Studies can explore how previous children from the male or female partners end influences treatment initiation.

5.3 Treatment Completion

Treatment completion was explored mainly as an exploratory aim for Chapter 3, but some aspects of treatment completion or non-completion emerged finding within the qualitative data in Chapter 4. The majority of the Black women in the dissertation study completed the recommended treatment plan. Within the quantitative analysis, younger age and absence of hormonal abnormalities led to increased odds of treatment completion. Though not specifically explored in Chapter 4, several of these factors were well supported. Women found that they were being rushed to initiate and complete treatment due to their advancing ages. While some women experienced issues with completing the treatment plan due to diminished ovarian reserve and poor embryo
quality. It was notable that although insurance played a significant role in treatment initiation, the effect of insurance could not overpower the inevitable biological factors that play a role in treatment completion or success.

5.4 Strengths

There were several strengths to this dissertation study. To the best of our knowledge, this was the first study to comprehensively explore the health seeking process of Black women with infertility. This study adds to the dearth amount of literature that provide understanding surrounding Black women with infertility. The study team worked synergistically to develop and adhere to a highly rigorous research protocol. Several reviewers were used to examine the quality and relevance of articles for Chapter 2. Chapter 2 and other infertility literature provided the opportunity for a priori development the measurements and ideas explored in Chapters 3 and 4. The infertility clinic was a large center with a robust electronic medical record database that provided relative ease of chart identification and for our sampling needs. They were well experienced in research standards and protocols and all parts of the study were conducted in a consistent and ethical manner. Also, the quality of documentation was high among clinical staff which led to a low number of missing values. Women who completed the qualitative interviews were diverse and provided unique points of views. Among the 13 women, one reported to be mixed race and one identified as
Black/Hispanic. All of the women attended the same fertility clinic therefore there was limited variation in treatment protocols and processes.

Although the recruitment procedures for the qualitative portion of the mixed methods study proved to have its challenges and needed to be modified after the study’s recruitment began. Many of the participants were often skeptical of the study team with two participants complaining directly to the research office at the infertility clinic, claiming invasion of privacy. Further, once some women enrolled in the study, there was heavy resistance towards providing social security numbers to receive the incentives for study completion. There were some instances where some women, despite providing verbal consent to participate, had asked for certain elements of their interviews to be omitted or further de-identified.

Despite these challenges in recruitment, support from both institutions helped to eliminate some of these barriers. Therefore, the original recruitment protocol was modified to have recruitment emails sent only by research staff that had the clinics name in the sending email address and a request to exempt collection of social security numbers for payment was submitted and ultimately accepted. Further, the method of utilizing the primary investigators picture on the study materials proved to be a reliable tactic that contributed to the majority of the women saying it influenced their
participation in the study. This process will be discussed in future publications on Black women’s mistrust of healthcare practitioners and researchers.

5.5 Limitations

The study was descriptive and exploratory in nature and the cross-sectional design causation could not be established. Also, the lack of a comparison group, preferably of non-Hispanic White women, would have added to our understanding if these influences are unique to Black women or not. The completion aim was mainly exploratory, therefore that sample was underpowered in the logistic analysis of that study outcome. However, some non-statistically significant results were still clinically significant and provided justification for further exploration. Finally, much of the data from the quantitative portion could not be compared to the qualitative findings because some aspects were not documented or present in charts. Although the systematic review in Chapter 2 provided some basis for measurement development for the main dissertation studies, the lack of uniformity of measurement variables and theoretical frameworks may have limited.

Further, this dissertation focused on treatment seeking behaviors not the decisions. Additional research would be necessary to incorporate the field of decision sciences to help us fully understand the experiences of Black women with infertility as they make meaningful decisions in high risk and low certainty situations. Also, the
sample was solely composed of partnered women and those already seeking evaluation. We have a limited understanding of the needs and experiences of Black women who are single or of other sexual identities in the larger community who have no clinical evaluations for infertility. Despite these limitations, this dissertation provides a strong foundation for future high level research examining the treatment experiences of Black women who struggle with infertility.

5.6 Future Directions

Overall, many of the facilitators and barriers identified within the dissertation showed the disease experience of infertility is a dynamic blend of psychobiological, clinical, and sociocultural factors that continuously influence treatment-seeking behaviors along the continuum. This dissertation was the first step in my program of research that will seek to improve the experiences of Black women who currently struggle with infertility while also focusing on several preventative measures to reduce treatment burdens. Findings from this dissertation can better equip nursing practice, interdisciplinary healthcare providers, educators, researchers, policymakers, and patients to better confront issues that inhibit treatment utilization for infertility within these groups. Additionally, this dissertation provides a strong foundation to support the need for use of mixed methods designs to reduce disparities in reproductive
endocrinology by enhancing our knowledge of the comprehensive experiences of Black women.

5.6.1 Implications for Nursing Practice

Nurses are at the forefront of health education, translating research into practice, and policy development. As we found in Chapters 3 and 4, Black women often waited twice as long as the recommended time frame to seek treatment for their infertility concerns. They further described this delayed period in seeking treatment as being attributed to a lack of awareness of disease symptomology, treatment options, and influence of age on treatment success. Nurses should continue to advocate to enhance comprehensive sexual education that also includes strategies to prevent infertility and promote healthy family building. This delayed treatment seeking was also found to be a result of insufficient education and referral by general practitioners. Delays could be attributed to limited or partial disclosure by the patient or lack of adherence to clinical guidelines for referral by providers. This could be as a result of biases from the providers part that women don’t have fertility problems and assumptions of their ability to pay for services. Nurse driven implicit biases trainings could help highlight and address these issues. It would also be worthy to explore the use of screening tools for infertility that would provide general practitioners an opportunity to identify infertility
symptom experiences among Black women in an evidenced based and standardized fashion.

5.6.2 Research

To our knowledge, this mixed methods study was the first study that comprehensively described the experiences of Black women who underwent evaluation for infertility and factors associated with treatment initiation. Replicating the study designs for Chapter 3 and Chapter 4 collecting from samples of non-Hispanic White women and Black women who are in regions with no insurance mandates and women that have not initiated fertility treatment seeking would be a worthy effort to undertake. Expanding the study samples and settings would allow for increased generalizability to more broad populations. Further, exploring these ideas among sexual and gender minorities could provide insight on other factors that may be barriers to healthy and affordable family building among those who are not clinically infertile, but require assisted technologies to conceive. This dissertation provided in-depth and critical analysis of several treatment seeking decision points along the continuum of Chrisman’s Health Seeking Process Model. Specifically, chapters touched on experiences within the pre-referral/pre-consultation period, early clinical evaluation, reproductive assessment and diagnostic testing, follow-up planning, treatment initiation, and ultimate completion of treatment. It would be worthy to explore these domains in-depth at each
individual stage for future theory development on treatment seeking among Black women experiencing infertility.

The findings of this study also lend way to research that develop and test interventions for prevention and early identification of infertility. The development of highly valid and reliable screening tools for psych-emotional responses to infertility, infertility symptom identification, and readiness for treatment should be explored. It would be important for these tools to be validated for populations who are most vulnerable to treatment inequities or lower utilization. Also, interventions should be developed and tested to address the factors that influenced fertility treatment in this study such as shared decision making, partnered decision making, and level of treatment agreement or understanding. For example, assessing the level of understanding to a specified protocol following the follow up visit may provide opportunities for additional teaching beyond standard care. This could allow for a more patient centered approach and increased utilization.

Further, exploration of how diverse treatment teams influence participation in research studies should be explored more in the realm of women’s health. In order to reduce disparities in research focus, researchers must contend with the biases and stigma Black women in the healthcare and beyond. Women in this study were open to discussing sensitive and personal issues because the primary investigator was of the
same race and perceptions of relatability were high. Future interventions could assess the quality of data collected or willingness to participate between researchers of different races. For example, having two research assistants of different cultures/races recruiting for a study and examining the differences in recruitment and attrition may be a worthy project to undertake.

5.6.3 Policy

There were numerous opportunities for policy development from the findings of this study. First, the women in the study discussed having large concerns regarding the lack of knowledge of infertility, types of treatment available, and the reduced efficacy of such treatments as they aged. The quantitative findings in Chapter 3 also supported this with the prolonged time Black women waited prior to seeking treatment or being provided with referrals for their infertility. This further demonstrates the need to enhance universal and comprehensive sexual education that not only incorporates aspects of disease prevention, intended pregnancy promotion, but also realistic education surrounding fertility lifespans and lifestyle risk factors that can contribute to decreased fertility.

Further, policy makers should continue to strive for more comprehensive and equitable coverage for infertility services. Many of these women had insurance coverage for some portion of treatment, but still faced large barriers in financing treatment.
medications. Efforts to collaborate with pharmaceutical companies to reduce treatment burden could also be explored. Similarly, women who resided in the region but had employees with headquarters outside of state lines were prohibited in taking part in these mandates. Also, legislation should support that those with underlying diseases that directly affect fertility should be given comprehensive coverage. Some of the women and their partners in chapter 4 were previously diagnosed with disorders that are known to impact fertility. For instance, if a woman experiences an emergent loss of a fallopian tube or a male is diagnosed with male factor fertility due to genetic concerns, there should be some additional support for their concerns.

Finally, clinical guidelines and organization-specific policies could be developed that help reduce the effect of potential implicit biases that may be leading to some of the disparities in reproductive endocrinology and Black women’s health. Standardizing screening for mental health, reproductive health, and other areas that disproportionately affect Black women may help in changing the clinical landscape for Black women. These early intervention strategies may help reduce the extent of services women need in their future care. This could be a venture that would benefit from multidisciplinary providers and clinicians.
5.7 Conclusion

As Black women seek treatment for infertility and consider initiating and completing recommended treatment plans, they are faced with numerous barriers and facilitators to care. However, the existing literature failed to describe characteristics of the Black women who sought care and potential factors that influence treatment decision outcomes. This dissertation helped elucidate the psychobiological, clinical, and sociocultural influences that affect Black women’s treatment experiences. We found that Black women could benefit from increased awareness regarding the risk, prevalence, and symptomology of infertility, comprehensive insurance coverage, culturally sensitive care, and also support for their partners as they consider whether or not to seek initiate, and complete treatment. These findings can serve as the foundation for practice, research, and policy aimed at providing safe, affordable, patient-centered, and evidenced based treatment options for Black women experiencing infertility.
Appendix A. Protocol for Obtaining Variables for Retrospective Chart Review

Study Title:

Determining Psychobiological, Clinical, and Sociocultural Factors that Influence Black Women to Initiate the Recommended Treatment Plan for Infertility: A Mixed Methods Study

| Principal Investigator | Morine Cebert  
| Duke University School of Nursing |
|-------------------------|--------------------------------|
| Sub Investigators       | Rosa Gonzalez-Guarda  
|                         | Eleanor Stevenson  
|                         | Susan Silva  
|                         | Peggy Shannon-Baker |
| Funding Sponsor:        | Duke University PhD Program Pilot Fund  
|                         | National Institutes of Health – National Institute of Nursing Research – 1F31NR018790-01A1 |

Original Objectives/Study Aims:

Aim 1. Determine the relationship among psychobiological, clinical, and sociocultural factors in Black women who underwent a reproductive endocrinology evaluation.

Aim 2. Identify psychobiological, clinical, and sociocultural factors that influenced initiation of infertility treatment among Black women who underwent a reproductive endocrinology evaluation.
Aim 3. Explore psychobiological, clinical, and sociocultural factors that predicted completion of infertility treatment among the Black women who initiated the recommended treatment plan.

**IRB Approval Number:** Pro00103220 Duke University Health System Institutional Review Board

**Steps for Abstraction:**

- Input the MPI number into Integramed/ARTworks
- Verify the chart meets inclusion
- Identify as Black, African American, or of African/Caribbean Descent
- Partnered or Married
- Completed an initial evaluation at Shady Grove Fertility from 2015* to Present at a Maryland location of Shady Grove Fertility
- Completed a Follow Up Visit where you were presented with a treatment plan.
- Have never completed previous infertility treatment at a location other than Shady Grove Fertility.
- Identify as female, between 18-44 years old

**Variables Being Abstracted from the Charts:**

- Age (number in years)
- Length of time experiencing infertility. (Number in months)
- Was there an abnormal genetic screen? (Yes or No)
- Body Mass Index (continuous)
- Any previous diagnosis:
  - of Hypertension? Yes or No.
  - of Thyroid disease? Yes or No.
  - of Diabetes? Yes or No.
  - of Hypercholesterolemia? Yes or No.
  - of Endometriosis? Yes or No.
  - of Polycystic Ovarian Syndrome? Yes or No.
  - of Fibroids? Yes or No.
  - of Pelvic Inflammatory Disease? Yes or No.
  - of Anxiety? Yes or No.
of Depression? Yes or No.
Is this treatment for Primary Infertility? Yes or No.
Did diagnosis tests reveal:
  Tubal disorder? Yes or No.
  Ovulatory Disorder? Yes or No.
  Male Factor? Yes or No.
  Unexplained Infertility? Yes or No.
Did diagnostic tests reveal any other abnormal female anatomy? Yes or No.
Abnormal hormones related to ovulation? Yes or No.
Abnormal Luteinizing Hormone? Yes or No.
Abnormal Estrogen? Yes or No.
Abnormal Follicle Stimulating Hormone? Yes or No.
Abnormal Anti-mullerian hormone? Yes or No.
Did the recommended treatment plan include:
  Oral medication only? Yes or No.
  Intramuscular or SC medication only? Yes or No.
  Combination of Oral and IM? Yes or No.
  Intrauterine Insemination? Yes or No.
  In vitro fertilization? Yes or No.
  Donor sperm? Yes or No.
  Donor egg? Yes or No.
  Gestational carrier? Yes or No.
  Did the patient use the Shared Risk to finance the treatment? Yes or No.
  Did the patient primarily use a qualifying insurance to finance treatment? Yes or No.
  Was the patient employed? Yes or No.
  Did the patient continue with the recommended treatment plan in 3 months? Yes or No.
  What was the first outcome of treatment? Yes or No.
  If pregnant, did it result in a live birth? Yes or No.
  Free text – any reasons possibly not seeking treatment in time, interesting findings, or other methods of financing.

Where to Find This Information:

Verifying the chart meets inclusion
  1. Identify as Black, African American, or of African/Caribbean Descent
2. Partnered or Married
3. Completed an initial evaluation at Shady Grove Fertility from 2015 to Present at a Maryland location of Shady Grove Fertility
4. Completed a Follow Up Visit where you were presented with a treatment plan.
5. Have never completed previous infertility treatment at a location other than Shady Grove Fertility.
6. Identify as female, between 18-44 years old
Many of this can be found by clicking:

- Patient Demographics. Table will pop up with this header:

![Patient Demographics Table]

OR

![Home Screen]
*The dates for the Follow up visit and previous treatment will typically always be in the “Initial Consultation Note”

**Exclude** patients who have had cycles of IUI or IVF previously.
Include women who have tried clomid only.

**Abstracting Data**

Year of Follow Up Visit (2015, 2016, 2017, 2018, 2019). **Record the year FUV occurred.**

Found in a note in the home tab that is often labeled as FUV. Body of the note tends to have a review of synopsis of testing so far.

Example below:

<table>
<thead>
<tr>
<th>FUV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reviewed baseline testing remarkable for DOR, tubal (L tube absent), male factor (morphology). Discussed challenges in attempting pregnancy with autologous treatment. Couple declined DC at this time. Discussed autologous IVF success rates are better than IUI, but they state they would like to start with treatments less invasive. They are aware they face lower pregnancy rates with IUI (12%) compared to IVF (7%) but prefer this route. Discussed both IUI and IVF, but specifically with IUI, the medications, success rates, logistics.</td>
</tr>
<tr>
<td>Plan:</td>
</tr>
<tr>
<td>- IUI x3 then FUV</td>
</tr>
<tr>
<td>- 56im plan: CC50mg, FSH 150 CD 5/7/8, Ovidrel, IUI</td>
</tr>
<tr>
<td>30 minute face to face consult, &gt;50% counseling.</td>
</tr>
</tbody>
</table>

Age (number in years). Record the whole number age.
Found in the initial consultation of the chart.
Sometimes updated in the FUV note, however, MDs have been repeating the ages from the Initial consult.

Example below:

<table>
<thead>
<tr>
<th>HISTORY OF PRESENT ILLNESS: The patient is a pleasant 35-year-old, para 0, who has been attempting conception for the last nine months.</th>
<th></th>
</tr>
</thead>
</table>
Length of time experiencing infertility. (Number in months).
Record the number of months. Found in the initial consult note

OR

- In the treatment plan tab

<table>
<thead>
<tr>
<th>Parity / Pregnancies @ Initial Consult</th>
<th>@ Initial Consult</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gravidity</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Prior preterm (&lt; 37 weeks)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prior Full Term (≥ 37 weeks)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prior Spontaneous Abortion</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Prior TAB</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Prior Ectopic</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prior Stillborn</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prior Living</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prior Biochemical</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Prior ART Live Births</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Gonadotropins</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Fresh ART</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Frozen ART</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Months trying to conceive</td>
<td>17</td>
<td></td>
</tr>
</tbody>
</table>
Discrepancies?

Then go back to the new patient questionnaire.

- takes you back to scanned documents. Located in the New Patient Questionnaire

Was there an abnormal genetic screen? (Yes or No or Declined)

Body Mass Index (continuous)

Both Abnormal Genetic screen and BMI found on patient home. Use the 1st BMI collected
Any previous diagnosis:
- of Hypertension? Yes or No.
- of Thyroid disease? Yes or No.
- of Diabetes? Yes or No.
- of Hypercholesterolemia? Yes or No.
- of Endometriosis? Yes or No.
- of Polycystic Ovarian Syndrome? Yes or No.
- of Fibroids? Yes or No.
- of Pelvic Inflammatory Disease? Yes or No.
- of Anxiety? Yes or No.
- of Depression? Yes or No.
- Found in the initial consult note OR in the New Patient Questionnaire

PAST MEDICAL HISTORY: The patient has no known drug allergies. She is currently taking for what sounds like and has also been taking for pain following a drainage.

PAST SURGICAL HISTORY: Drainage of a Bartholin cyst abscess.

PAST GYN HISTORY: The patient's menstrual cycles are every 26 days and last for five days. Her last menstrual period began . Her last Pap smear was and was normal. The patient has had significant mid-cycle pelvic pain over a wide period of time. She has had a number of ultrasound which have not revealed any pathology.

SOCIAL HISTORY: The patient . She does not smoke cigarettes.

SPouse: Credit manager. He has no known drug allergies, takes no medications, has had no surgery and does not smoke cigarettes.

PRIOR EVALUATION: The patient had a pelvic ultrasound due to pelvic pain . Her uterus was 8.1 x 6.7 x 4.5. She had a right calcified intramural fibroid 2.9 cm, a left anterior subserosal fibroid 1.2 cm, and a lateral subserosal fibroid 1.5 cm. Her right ovary was 2.0 x 2.3 x 2.1. Her left ovary was 2.3 x 1.9 x 1.9.

Is this treatment for Primary Infertility? Yes or No.

Diagnosis of Infertility will be Primary if no live birth resulted (using WHO definition).

Can use the initial consult, treatment plan tab, or NP Questionnaire.

treatment plan tab:
NP Questionnaire

Did diagnosis tests reveal:

Tubal disorder? Yes or No.
Ovulatory Disorder? Yes or No.
Male Factor? Yes or No.
Unexplained Infertility? Yes or No.
Found typically in the FUV Note or other progress notes.

FUV

Reviewed baseline testing remarkable for DOR, tubal (l. tube absent), male factor (morphology). Discussed challenges in attempting pregnancy with autologous treatment. Couple declined DE at this time. Discussed autologous IVF success rates are better than IUI, but they state they would like to start with treatment less invasive. They are aware they face lower pregnancy rates with IUI (12%) compared to IVF (21%) but prefer this route. Discussed both IUI and IVF, but specifically with IUI, the medications, success rates, logistics.

Plan:
- IUI x3 then FIV
- Stim plan: CC150mg, FSH 150 CD 5/7/9, Divided, IUI
- 30 minute face to face consult, >50% counselling.

Diagnosis: Male teratozoospermia

Plan:
- IUI/ICSI possible PGS
- Hyst resection of submucosal fibroid with GYN prior to ET (gt. may cycle if does PGS, freeze embryos and then address)

Protocol:
- OCP Antagonist with starting dose of 225/150, hCG vs. Lupron trigger
- Planned ICSI
- Possible PGS

Or HSG or Ultrasound Notes

Findings: Uterus unremarkable, normal size and shape. Tubes patent with bilateral fill and spill.

Impression/Conclusion: Normal study

Abnormal Labs?

Normal Ranges Will Be for the 1st documented labs, whether in *results or in the progress notes*

LH: 0 – 6.7 IU/L
Estrogen: 25-200 pg/ml, but you want around 50.
FSH: should be below 10.
AMH: greater than 1 and but no higher than 10* for PCOS.

Recommended Treatment Plan
Usually in FUV notes:
Use this to code medication and actual plan type.

Examples Below:

<table>
<thead>
<tr>
<th>Plan - ganirelix, 150/37.5, lupon vs HCG trigger, ICSI, ESET</th>
</tr>
</thead>
</table>

- **PLAN:** OCPs, mock embryo transfer already done, antagonist, planned Lupron trigger, 100-75 g.m. dosing, ICSI to be determined, plus assisted hatching.

- Unexplained infertility
  
  Pt clomid 50mg CD 3-7 backCD 12 for monitoring. Couple will proceed with treatment after wedding next year if not pregnant.
  
  30min face to face consult with 20min spent in counseling and coordination of care.

- Discuss moving forward with IVF. Unfortunately this is not a covered benefit under their plans and they are requesting to undergo 1 to 2 cycles of FIV. Given the patient’s age and slightly lower AMH, we discussed a Clomid gonadotropin treatment cycle with 100mg of Clomid on days 3 to 7 and 150 international units of FSH on cycle day 7, returning cycle day 9 for plan monitoring. We will plan for FIV with this treatment cycle and monitor the total follicle count closely post-ovulation. In addition, the patient is taking prenatal vitamin. We discussed vitamin D supplementation as her vitamin D was found to be low.

<table>
<thead>
<tr>
<th>Consult</th>
<th>Y/N primary infertility</th>
</tr>
</thead>
<tbody>
<tr>
<td>day 3</td>
<td>low fs h&lt;5.4 e2 35.9 h&lt;3.22 e2 &lt;41 calculated luteal phase deficit seen cavity amb 5.4</td>
</tr>
<tr>
<td>beg nl cavity bl fill and spill of nl appearing tubes</td>
<td></td>
</tr>
<tr>
<td>sa 4.3 cc 10/8/97</td>
<td></td>
</tr>
</tbody>
</table>

- Unexplained infertility
  
  Low vit D - take supplementation
  
  Low hcg - MCV - take FSH

- Declined genetic screening

  plan cc: 50+lib 25 in day 9 (101)

  would need injections class

  20 min spent in direct face to face consult with the couple > 50% in counseling and coordination of care ph

**Medications:**

OCPs & Clomid are Oral Medications

Anything else is typically IM/SC

Oral Only –
**Initiate versus Not Initiate within 3 Months.**

**Example of Initiated**: FUV was 11/2018, started treatment cycle on 11/30

There may be a progress note that states OK to START

**Outcome of First Cycle**
- Pregnant if Clinical Intrauterine Pregnancy, Biochemical Pregnancy, or Ectopic Pregnancy
- Not Pregnant if states Not Pregnant in the Cycle form - open CYCLE FORM
### Qualifying Insurance?

**Yes** -

<table>
<thead>
<tr>
<th>Type</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>FET</td>
<td>Not Pregnant</td>
</tr>
<tr>
<td>IVF</td>
<td>Not Pregnant</td>
</tr>
<tr>
<td>IVF</td>
<td>Not Pregnant</td>
</tr>
<tr>
<td>FET</td>
<td>Clinical Intrauterine</td>
</tr>
<tr>
<td>IVF</td>
<td>Biochemical</td>
</tr>
</tbody>
</table>

**Any Limitations?**

There may be discrepancies or difficult to read sections. Note in the notes section.
Appendix B. Blank Demographic Data Survey

Demographic Data Sheet for Interview Participants

1. What is your age? __________

2. What is your sex?
   - Female ○ Male ○

3. What is your marital status?
   - Single ○ Married ○ Separated ○ Divorced ○ Widowed ○

4. What is your current employment status?
   - Unemployed/Homemaker ○ At least part-time ○ Full time ○ Self-Employed ○ Other ○

5. What is your combined annual income?
   - Less than $60,000 ○ $60,001 to $70,000 ○ $70,001 to $80,000 ○
   - $80,001 to $90,000 ○ $90,001 to $100,000 ○ Greater than $100,000 ○
5. With which racial or ethnic category do you identify, check all that apply?

African American/Black ○ Asian/Pacific Islander ○ Caucasian ○ Latino ○

Other: ______________________

6. What is the highest level of education you have obtained?

High School ○ Some College ○ College ○ Graduate/Professional ○

7. What group of religious beliefs would you most subscribe to?

Christian ○ Catholic ○ Muslim ○ Jewish ○ Atheist ○ Agnostic ○ Prefer not to answer ○

8. How long would you say, using a number in years or months, did you wait until you sought care for your fertility concerns?

_______ year(s) or _______ month(s)
Appendix C. Interview Script Initiated.

**Script to be read to participant:** Thank you for your participation today. My name is [Interviewer name], a PhD student at Duke University School of Nursing. This interview is being conducted as part of a research project discussed with you in the informed consent. The interview will take about 45 to 60 minutes and will be audio recorded so I may accurately document the information. The audio recording and anything else that you share with me today is going to be used for purpose of the research study and will not be shared with anyone outside of the study team. Names, places, or other identifiers that can be used to reveal your identity will not be used. If at any point you feel comfortable in responding to one of the questions, you can choose to not answer it. At this time, we will begin the interview. Is it okay to start recording?

**Opening Questions:**

- Tell me about your experiences with trying to have a baby before you came to Shady Grove.
- What alarmed you to this being a problem where you knew you needed help?

**Psychobiological Characteristics**

- How would you describe your general health?
- What were your perceptions of infertility before coming to Shady Grove?
- Tell me about how your inability to have a child (at that point) impacted your life?
- Were there any points where you felt really sad or anxious?
- Tell me about those experiences.

**Clinical Characteristics**

- Tell me about how you came to Shady Grove.
- How was your experience in your first visit with Shady Grove?
  a. Who did you interact with?
  b. How were those experiences?
  c. How did you feel about your provider(s)?
What were your thoughts after the first visit?
   a. Did anything surprise you?
   b. Did anything trouble you?
   c. What did you think about your proposed treatment plan?

Explain to me the process of deciding to initiate the recommended treatment plan
   a. Were there any fears or hesitations you had about continuing care?

Socio-cultural Characteristics

Tell me about any concerns you had financially about treatment?
Did your insurance cover treatment?
   a. Did finances play a role in your decision to continue care?

Tell me about your partner.
   a. Explain the role your partner played in your decisions of infertility treatment
   b. Who in your social circles knew about your difficulty with having a child.

Has your faith played a role in your decision?
   a. Did you tell anyone in your faith community about this issue?

As a Black woman, do you think your racial identity promoted or prevented any aspect of your decision to initiate the treatment?

How do you feel like the community around you understands infertility?

If you met another woman, who was similar to you, what advice would you give her as she decides whether or not to seek and continue care?
Appendix D. Interview Script Did Not Initiate

Script to be read to participant: Thank you for your participation today. My name is [Interviewer name], a PhD student at Duke University School of Nursing. This interview is being conducted as part of a research project discussed with you in the informed consent. The interview will take about 45 to 60 minutes and will be audio recorded so I may accurately document the information. The audio recording and anything else that you share with me today is going to be used for purpose of the research study and will not be shared with anyone outside of the study team. Names, places, or other identifiers that can be used to reveal your identity will not be used. If at any point you feel comfortable in responding to one of the questions, you can choose to not answer it. At this time, we will begin the interview. Is it okay to start recording?

Opening Questions:

- Tell me about your experiences with trying to have a baby before you came to Shady Grove.
- What alarmed you to this being a problem where you knew you needed help?

Psychobiological Characteristics

- How would you describe your general health?
- What were your perceptions of infertility before coming to Shady Grove?
- Tell me about how your inability to have a child (at that point) impacted your life?
- Were there any points where you felt really sad or anxious?
- Tell me about those experiences.

Clinical Characteristics

- Tell me about how you came to Shady Grove.
- How was your experience in your first visit with Shady Grove?
  - Who did you interact with?
  - How were those experiences?
  - How did you feel about your provider(s)?
- What were your thoughts after the first visit?
  - Did anything surprise you?
e. Did anything trouble you?
f. What did you think about your proposed treatment plan?

- Explain to me the process of deciding to not initiate the recommended treatment plan
  b. Were there any fears or hesitations you had about continuing care?

Socio-cultural Characteristics

- Tell me about any concerns you had financially about treatment?
  Did your insurance cover treatment?
  b. Did finances play a role in your decision to continue care?

- Tell me about your partner.
  c. Explain the role your partner played in your decisions of infertility treatment
  d. Who in your social circles knew about your difficulty with having a child.

- Has your faith played a role in your decision?
  b. Did you tell anyone in your faith community about this issue?

- As a Black woman, do you think your racial identity promoted or prevented any aspect of your decision to initiate the treatment?
- How do you feel like the community around you understands infertility?
- If you met another woman, who was similar to you, what advice would you give her as she decides whether or not to seek and continue care?
References


Bogart, L. M., Wagner, G. J., Green Jr, H. D., Mutchler, M. G., Klein, D. J., McDavidt, B., ... & Hilliard, C. L. (2016). Medical mistrust among social network members may contribute to antiretroviral treatment nonadherence in African Americans living with HIV. *Social Science & Medicine, 164*, 133-.


Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open, 4*(1), 21582440145226333


179


182


NVivo qualitative data analysis software; QSR International Pty Ltd. Version 12, 2018.


Biography

Morine Cebert earned her Bachelor of Science in Nursing degree from Boston College in 2012 where she was a Keys to Inclusive Leadership in Nursing Scholar. She continued her education at Winston Salem State University in 2015 where she was selected as a WSSU-Duke School of Nursing Bridge to the Doctorate scholar. While there, she complete a rigorous graduate program and additional research courses and earned her Masters of Science in Nursing with High Honors and is a certified Family Nurse Practitioner. While a Bridge Scholar, she began her scholarly entry into the field of reproductive endocrinology and completed a thesis that examined marital quality between women who conceived via in vitro fertilization and women who did not use assisted reproductive technologies.

Following the completion of her graduate program, Morine enrolled into Duke University School of Nursing (DUSON) where she is a Robert Wood Johnson Foundation Future of Nursing Scholar and funded as a pre-doctoral fellow at the National Institute of Nursing Research of the National Institutes of Health. Morine will continue her work reproductive endocrinology health disparities as a National Clinician Scholar at the University of Pennsylvania. During this fellowship, Morine will enhance her skills in leadership, practice, and policy development to build her program of research that seeks to improve the lives of Black women across the world.