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A Qualitative Descriptive Study Exploring Infertility Help-Seeking Among African American Women

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A QUALITATIVE DESCRIPTIVE STUDY EXPLORING INFERTILITY HELP-SEEKING AMONG AFRICAN AMERICAN WOMEN

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ABSTRACT

BACKGROUND: Failure to achieve pregnancy (infertility) affects over 6 million women ages 15–44 in the United States. African American women have more difficulty getting pregnant than White women but are less likely to seek help for infertility. According to the current research, there are several factors (cost, insurance coverage, etc.) that create difficulty for women to seek help to get pregnant. However, little is known about the factors that influence or impede infertility help-seeking among African American women. The purpose of this study was to explore the barriers and facilitators to infertility help-seeking among African American women.

METHODS: Factors affecting infertility help-seeking among African women were explored using a qualitative descriptive design. Descriptive statistics were obtained using sample characteristics and an adapted version of the Cardiff Fertility Knowledge Scale which examined participants' knowledge related to female fertility. Qualitative data were obtained through in-depth, semi-structured interviews with each participant (n=12). Interviews were transcribed verbatim and analyzed using thematic analysis and NVivo 12.

RESULTS: The themes that emerged from the interviews were: barriers, facilitators, and recommendations for infertility help-seeking. The most common barriers reported were knowledge and awareness, challenging experiences with fertility specialists, perception of treatments, religious beliefs, and infertility stigma. Facilitators to infertility

help-seeking included the significance of a strong support system and cultivating resilience in the face of infertility challenges. Recommendations to improve infertility help-seeking were to increase African American women's awareness and understanding of infertility and its treatments, improve infertility care to ensure consistent provision of care and resources across all fertility clinics, and a desire for greater openness among African American women in sharing their infertility experiences and seeking assistance. **CONCLUSION:** This study identified various factors influencing the decision of African American women to pursue infertility treatment. The study findings offer valuable insights that can inform clinical practice, guide future research, and shape policy initiatives.

Keywords: African American women, infertility, fertility treatments, help-seeking, qualitative research

DEDICATION

I would like to dedicate this dissertation to my husband, Andrew. Thank you for your support and love throughout this journey. I am so appreciative of your patience and kindness through this process. To Aiden and Averi (my children), thank you for being the easy part of life. I enjoy being your mom and I love you both so very much. To my parents, Richard and Phyllis Gosa, thank you for instilling the values in me to persevere and always finish the task. I am forever grateful for the sacrifices you both have made for Brian and me to have the life that we've had. To my parents in love, Dr. Willie and Carol Wells, Jr., thank you for your constant prayers, love, encouragement and most of all, your Andrew. To my brothers and sister, Brian, Trey, and Valencia, thank you all for being great role models and showing me firsthand how to set goals and achieve them. To my friends, especially my sisters Courtney, Trista, and Valencia, words can't express how our daily talks and texts motivated me to continue to push forward. To the Coalition, thank you for your advice, friendship, and support. To the women in my study, thank you for sharing your stories with me. I am so honored to have had the privilege in speaking with you and I am forever grateful.

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CHAPTER 1

INTRODUCTION

Infertility is a global public health concern impacting over 180 million women in developing countries (Macarenas et al., 2012). In the United States, over 6 million women aged 18 – 44 are affected by infertility (Centers for Disease Control and Prevention [CDC], 2021). Despite the introduction of state laws and policies promoting equitable access to infertility care, many women, especially of marginalized communities, remain untreated or undertreated (American Society for Reproductive Medicine, 2021). African American women in the United States have twice the prevalence of infertility (14%) than non-Hispanic White women (7%), and they are half as likely to seek treatment (Chin et al., 2015). Racial disparities exist in the utilization of infertility services with older, wealthy, educated, and married White women most likely to receive treatment (Chin et al., 2015). Previous studies revealed that up to 50% of White women who experience infertility seek treatment while approximately only 8% of African American women seek treatment (Chandra et al., 2015). There are many factors that have been attributed to low rates of infertility service utilization, such as high cost, lack of insurance coverage, access and availability of services, income, restrictive laws and policies, help-seeking behaviors, lack of fertility knowledge, and stigma (Chandra et al., 2015; Chin et al., 2015; Shapiro et al., 2015). However, the factors contributing to

disparities in infertility help-seeking among African American women have not been widely explored.

Parenthood is one of the major transitions in adult life for both men and women among individuals who want children (Guzzo & Hayford, 2020). The inability to conceive a child has been associated with anger, depression, anxiety, marital problems, sexual dysfunction, social isolation, and lower quality of life (Chin et al., 2015; Greit et al., 2013). Women often experience stigma, sense of loss, and diminished self-esteem with infertility (Taebi et al, 2021). For women of color, including African American women, the negative effects of infertility are heightened because infertility is highly stigmatized in their culture (Greil et al., 2010). It is important to understand the barriers to seeking help among African American women to mitigate the negative effects of infertility.

Previous studies revealed that infertility help-seeking among women in the United States is multifactorial. Most notable facilitators to infertility help-seeking include high desire for parenthood, partner and social support, and advanced reproductive health literacy (Greil et al., 2013; Johnson & Johnson, 2009). Internalized stigma, cost of services, career obligations, and low or no social support were common barriers to infertility help-seeking (Greil et al., 2013; Slauson-Blevins et al., 2013). While infertility help-seeking has been explored in the United States, African American women are not well-represented. Previous studies exploring infertility help-seeking included samples of mostly highly educated high-income, White women. In addition to study samples mostly including White women, research is conducted within the fertility clinic setting, excluding women who do not seek help. This exclusion limits understanding the factors

that affect infertility help-seeking to only those who are seeking or sought help. Because of African American women's increase rates of infertility but unlikeliness to seek help, it is important to understand the factors that influences their decision to seek help. This will add an important perspective to the literature that could later help in developing interventions or policy to improve infertility service utilization among this population.

Problem Statement

Despite advancements in infertility care, African American women continue to lag in the use of infertility services. African American women have a higher infertility prevalence rate and wait longer before seeking care compared with White women (Wiltshire et al., 2019). Research on infertility help-seeking has largely focused on White women and women who are seeking treatment. Factors affecting infertility help-seeking among African American women, including women who do not seek help, are not well understood.

Background and Significance of the Problem

Infertility

Many women around the world report experiencing infertility. In the United States, approximately 6 million women of childbearing age (15-44) have experienced infertility (CDC, 2021). For women, infertility can be a serious health issue that can impact various aspects of their lives, including quality of life (Hasanpoor-Azghdy et al., 2014). Infertility is not always a preventable condition, but there are some preventable factors that can be avoided (smoking, sexually transmitted infections [STIs], overweight,

etc.) (Macaluso et al., 2010). The prevalence of preventable risk factors of infertility disproportionately increases rates of infertility in minority populations because of social and racial disparities in health status (Chandra et al., 2005). African American women report infertility more frequently than White women but do not seek infertility services at the same rate as White women. Previous studies suggest that despite economic and educational status, marital status, and risk factors for infertility, African American women are two times more likely to suffer from infertility than White women (Wiltshire et al., 2019). Because African American women are underrepresented in infertility research, researchers suggest infertility rates among African American women may be higher than reported while infertility rates of White women are decreasing (Seifer et al., 2010).

Fertility Knowledge and Beliefs

As African American women's decision process to seek infertility services is not extensively studied or known, African American women's fertility knowledge is also unknown. The current state of fertility knowledge among women of childbearing age is minimal and many women are unaware of their fertility health status until they begin to have issues with becoming pregnant (Macaluso et al., 2010). Due to a lack of participation in medical research, studies exploring women's fertility knowledge and beliefs do not depict an adequate representation of minority groups, more specifically African American women (Selfer et al., 2007; Wilshire et al., 2019). In most studies, study participants mostly identify as White women, which does not provide much information as to what African American women know about fertility (Macaluso et al.,

2010; Selfer et al., 2007; Wilshire et al., 2019). Fertility knowledge has been a concept identified in playing a role in how women make decisions regarding their fertility health. With the underrepresentation of African American women in fertility and infertility research and low infertility service utilization, it is difficult to understand the burden of infertility in this population (Wellons et al., 2008).

Infertility Service Utilization in the United States

Limited access to affordable infertility care, hinder the realization of some people's desires to create the families they envision (Kessler et al., 2013). These barriers create treatment gaps and health disparities for disadvantaged populations such as minorities. In the United States, economic, racial, and other disparities exist in access to infertility services and in treatment outcomes (ASRM, 2021). Although African American women have a higher rate of experiencing infertility than White women, they are less likely to seek infertility care (Wellons et al., 2008; Wiltshire et al., 2019). According to an analysis of the National Survey of Family Growth's (NSFG) data, 13% of White women reported ever seeking help to get pregnant compared to 7% of African American women (Weigel et al., 2020). Economic disparities are often listed as a major barrier to infertility service utilization, but for minority populations, such as African American women, there may be other contributors to not seek infertility services. Infertility service rates persist even in states that mandate insurance coverage of infertility services (Chin et al., 2015). Social and cultural factors such as stigma and cultural emphasis on privacy could also play a major role in African American women seeking infertility services (ASRM, 2015).

Infertility Help-Seeking

Because infertility has become a public issue around the world, the decision-making process for seeking help has become a concept requiring increased attention in the medical world. Previous studies regarding infertility help-seeking reported that this process may be related to personal cues such as fertility knowledge and treatment beliefs or social factors such as fear of being labelled infertile (Bunting & Boivon, 2007). Although there has been an increase in infertility service options, women who need these services do not always seek help (Johnson et al., 2009). Despite the prevalence of infertility, African American women do not seek help for infertility at the same rate as White women. In the states with state-mandated coverage for fertility treatments, African American women continue to lag in infertility help-seeking. Because of this, there has been a greater need to understand infertility help-seeking among women who meet criteria for infertility services but do not seek help (Bunting & Boivon, 2007).

Study Purpose

The purpose of this study is to explore the barriers and facilitators to infertility help-seeking among African American women.

Study Aims and Research Questions

The specific aims of this qualitative descriptive study are:

Specific Aim 1: Describe the facilitators and barriers to infertility help-seeking among African American women.

Research Question 1.1: What are the facilitators to infertility help-seeking among African American women?

Research Question 1.2: What are the facilitators to infertility help-seeking among African American women?

Specific Aim 2: Explore African American women's beliefs related to infertility and infertility services.

Research Question 2: What are African American women's beliefs about infertility and infertility services?

Specific Aim 3: Investigate how African American women's fertility knowledge impacts infertility help-seeking.

Research Question 3: What role does fertility knowledge play in shaping infertility help-seeking in African American women?

Specific Aim 4: Explore how infertility stigma impacts infertility help-seeking among African American women.

Research Question 4: How much of a role does infertility stigma play in infertility help-seeking among African American women?

Introduction of Theoretical Framework

The Traits-Desires-Intentions-Behavior model (TDIB) developed by Miller (1994) is the theoretical framework for this study. The TDIB model was specifically designed to describe and predict fertility decision making and reproductive behavior. It is a sequence of 4 phases in which three psychological stages lead to a fourth phase, the

behavioral phase. According to the TDIB, motivational traits are conceptualized as latent dispositions to be positively or negatively motivated toward fertility-related experiences (Miller, 1994). Miller (1994) explains that motivational traits are people's dispositions to respond in specific ways under certain conditions. Motivational traits for fertility may include age, race, ethnicity, fertility perceptions (beliefs), religion, level of education, income, family support, level of fertility knowledge and social norms. These motivational traits are used to formulate fertility desires, which represent what an individual would like to happen. Wanting to achieve a goal through action represents the desire concept of the TDIB model. This could be expressed through a woman wanting or not wanting to have a child or a woman wanting to seek fertility treatments to have a child. Fertility desires may be affected by personal values (Miller, 1994). At the time an individual decides to pursue a particular fertility goal, desires become fertility intentions. In accordance with the TDIB model, fertility intention is considered the most influential construct affecting reproductive behavior because it signifies an individual's or couple's actual plan to have or not have child or children (Mencarini et al., 2015). The last phase is when intentions lead to behaviors to achieve a specific fertility goal. This is the culmination of the psychological sequence of traits, desires and intentions that regulates and determines subsequent reproductive decision making and behaviors. Understanding the full trajectory of this model will allow for better understanding of the complexity of infertility help-seeking and identify facilitators and barriers African American women may face when dealing with infertility.

Introduction of the Design and Methods

Study Design

The goal of this qualitative study was to explore African American women's decision processes related to infertility help-seeking. Qualitative designs allow researchers to gain a deeper understanding of personal experiences and gain insight on the meanings people attribute to their attitudes, beliefs, or behavior (Holloway & Galvin, 2016). For this study, the qualitative descriptive approach was chosen because it attempts systematically to describe a situation, phenomenon or problem (Kim et al., 2017). This study used descriptive statistics obtained from an adapted version of the Cardiff Fertility Knowledge Scale along with semi-structured interviews to gain insight from participants regarding infertility help-seeking, which is a poorly understood phenomenon among African American women. This approach assisted in developing a clear description of this phenomenon based on the participants' perspective (Sandelowski, 2000).

Sample and Setting

Sampling strategies that were used to recruit participants for this study included criterion and snowball sampling. Social media platforms such as Facebook and Instagram, study recruitment flyers, and word of mouth were avenues used to recruit participants for this study. Utilizing social media platforms for recruitment creates a new and cost-effective way to reach a larger number of potential participants with minimal risk for breeching privacy (Gelinas et al., 2017). Recruiting through social media platforms have also been effective when trying to engage study participants that are difficult to find or if the study is related to a sensitive or stigmatized topic (reproductive

health, mental disorders, etc.) (Arigo et al., 2018). African American sorority, social groups, and women's health support groups were also utilized to recruit potential participants. Also, enrolled participants were utilized to refer other potential participants to the study. Participants met criteria for this study if they (a) were between 18 – 44 years of age; (b) identified as Black or African American; and (c) were unable to get pregnant after 12 months of trying. Participants were excluded if they were experiencing secondary infertility (unable to get pregnant after previously being able to get pregnant). The justification for excluding women experiencing secondary infertility is based on the acknowledgment that they may encounter unique challenges distinct from those faced by women experiencing primary infertility.

Data Collection

After enrollment in the study, participants completed one survey which questions were adapted from the Cardiff Fertility Knowledge Scale. This survey is a 13-item questionnaire developed to assess fertility knowledge which is known to impact infertility help-seeking (Bunting et al., 2013). After completion of survey, each participant was contacted to participate in one interview.

To gain personal perspective and provide an in-depth understanding of the phenomenon, infertility help-seeking, semi-structured interviews were conducted. Telephone interviews were used to collect data and interviews were recorded and transcribed verbatim. An interview guide was followed, and questions were asked in an open-ended style to encourage deeper and insightful answers. Using open-ended questions allows participants to freely answer interview questions based on their

knowledge, feeling, and/or understanding of the phenomenon (Weller et al., 2018). Interview sessions took approximately 45 to 60 minutes to complete. To protect confidentiality of participants, responses were securely stored on a password protected computer and personal information was de-identified. Because this a qualitative study, strategies were used to establish trustworthiness and credibility of the data.

Data Analysis Plan

The data analysis plan included transcribing all participant's responses, extracting important statements to formulate clustered themes (coding), interpreting the data, and presenting data using figures and tables (Creswell & Poth, 2018). During the analysis process, discussions with committee member were conducted to develop the the final interpretation of the data. Qualitative analysis computer software was utilized to aid in storing and organizing data.

Definitions

This section provides key terms and the definitions of key terms that will be used throughout this dissertation.

Fertility

Fertility is defined as the ability to conceive children (CDC, 2021).

Childbearing Age

The age at which a woman may become pregnant. Defined as the timeframe when menstruation begins (menarche) and ends (menopause).

Infertility

Infertility is defined as failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse (CDC, 2021). After the age 35, infertility is defined as failure to achieve a pregnancy after 6 months or more of regular unprotected sexual intercourse (CDC, 2021. Infertility is further defined as:

Primary infertility: the inability to become pregnant

Secondary infertility: the inability to become pregnant after having a least one prior pregnancy

Impaired Fecundity

In some cases, infertility may be related to a condition called impaired fecundity. Impaired fecundity is defined as the inability to either become pregnant or carry a pregnancy to live birth (CDC, 2021). Women who suffer from impaired fecundity are often included in infertility rates.

Infertility Services

Infertility services is a term used to describe the treatment options used for infertility. Infertility services are divided into three subgroups: diagnostic services, treatment services, and fertility preservation. Infertility services includes fertility

counseling (advice), fertility testing, fertility drugs, artificial insemination (IUI), assisted reproductive technology (ART), and cryopreservation (Weigel et al., 2020).

Assisted Reproductive Technology

Assisted reproductive technology (ART) is a term used to define infertility treatments that include surgical procedures that remove eggs from a woman's ovaries, combine them with sperm in the laboratory, and return them to the woman's body or donate them to another woman (CDC, 2021). The most common ART procedures are vitro fertilization-embryo transfer (IVF-ET), gamete intrafallopian transfer (GIFT), zygote intrafallopian transfer (ZIFT), and frozen embryo transfer (FET).

Infertility Help-Seeking

Infertility help-seeking is a concept developed to describe the process or decision to seek or not seek medical or professional help for infertility (Sherrod & Houser, 2013).

Involuntary Childlessness

Involuntary childlessness is a term used to describe people who wanted to have children with their partner but, either with or without fertility treatments, were unable to conceive (Lechner et al., 2007).

Fertility Knowledge

Fertility knowledge is a multi-dimensional concept that includes having information about the female menstrual cycle, pregnancy potential within each menstrual cycle, infertility risks, fertility treatment options and contraception options (Mu, 2016).

Fertility Beliefs

Fertility beliefs are defined as women's attitude towards fertility and fertility health (Bunting et al., 2013).

Fertility Intention

Fertility intentions are a person's desire or intent to have a child(ren) and the timing to have a child(ren). Fertility intentions also include the desire or intent to seek medical help for infertility if needed (Bunting et al., 2013).

Summary

Failure to achieve pregnancy (infertility) affects over 6 million women in the United States (CDC, 2021). African American women have more difficulty getting pregnant than White women but are less likely to seek help for infertility (Wiltshire et al., 2019). According to the current research, there are several factors (cost, insurance coverage, etc.) that create difficulty for women to seek help to get pregnant (Wiltshire et al., 2019) However, little is known about the factors that influence or impede infertility help-seeking among African American women. Only one study was identified that specifically examined the factors that influenced African American women to seek,

initiate and complete treatment for infertility (Cerbert-Gaitors et al., 2022). However, this study did not include African American who were unable to get pregnant that did not seek help for infertility. It is suggested that further research regarding infertility help-seeking should include African American women who do not seek help to better understand the difficulty and barriers they face when dealing with infertility. This chapter introduced the problem, provided background and significance of the problem, identified the purpose, specific aims and research questions, provided a theoretical framework, and defined important terms for a qualitative descriptive study exploring infertility help-seeking among African American women.

CHAPTER 2

REVIEW OF LITERATURE

The purpose of this chapter is to gain insight to the current state of the science of infertility help-seeking and related concepts through an integrative review of the literature. This chapter will also discuss: (a) concepts of interest; (b) literature review search strategy; (c) analysis of the literature relative to concepts; (d) theoretical framework; (e) study design and methods; and (f) ethical issues related to the sample of this study.

In the United States, approximately 10% of women aged 15 - 44 have difficulty becoming pregnant or staying pregnant (infertility) (CDC, 2021). Infertility is considered an important reproductive health issue and African American women face challenges with seeking and receiving equitable treatment of infertility (Prather et al., 2018). Previous studies have shown that African American women are more likely to experience infertility compared with White women but are less likely to seek help (Chin et al., 2015). Despite this evidence, it is unclear the exact cause of this disparity because African American women are inadequately represented in these studies, which suggest this disparity may be greater than reported (Wellons et al., 2008). Generally, studies correlate disparities in infertility help-seeking to cost and access of infertility services, infertility stigma, lack of knowledge, and misconceptions surrounding infertility and infertility services (Ibrahim & Zore, 2020).

Research attempting to understand the disparity of infertility help-seeking is conducted among women who are already seeking help for infertility but not within the population of women who may be experiencing difficulty becoming pregnant but are not seeking help (Chin et al., 2015). This population may not recognize their difficulty becoming pregnant as infertility and may not be aware help is needed. African American women are susceptible to this because they are twice as likely to experience infertility but do not seek help at the same rate (Armstrong & Plowden, 2012). Currently, there is a lack of research understanding how African American women describe the barriers and facilitators that impact infertility help-seeking (White et al., 2006). The purpose of this qualitative descriptive study was to explore African American women's infertility help-seeking by identifying barriers and facilitators.

Epidemiologic Basis and Concepts of Interest

Fertility

Fertility is defined as the ability to conceive or have children (CDC, 2021). Both women and men become fertile in their adolescent years after puberty (De Silva & Tschirhart, 2016). For women, fertility starts with the onset of ovulation and menstruation (menarche) and begins to decline approximately 5 to 10 years before menopause (end of menstruation) (ASRM, 2012). For men, fertility declines much later than women, allowing them to have a wider fertile window. Since the 1950s, the average of children per woman worldwide has decreased from five to two children (Hamilton et al., 2021). At 2.08 children per woman, the fertility rate in the United States has been continuously below the global average of about 2.4 children per woman over the last

decade (Chandra et al., 2005). However, in 2020, the general fertility rate for women aged 15 – 44 in the United States was 55.8 births per 1,000 women, which is a 4% decline from the rate of 2019 (Hamilton et al., 2021). Of those declining fertility rates, African American women had a 4% fertility rate decline compared to 2019 rates (Hamilton et al., 2021).

Infertility

Infertility is defined as the failure to establish a clinical pregnancy (confirmed by a high level of the pregnancy hormone beta human chorionic gonatropin (βHCG) (or ultrasound) after 12 months of regular and unprotected intercourse (CDC, 2021). Infertility affects over 180 million people globally and over 6% of married couples in the United States (Inhorn & Patrizio, 2015; Kessler et al., 2013). Infertility may arise from male factors, female factors, a combination of both, or from an unknown cause (Brugo-Olmedo et al., 2001). When the cause of the infertility is found to come from the female partner, it is considered female infertility or female factor infertility.

In a national survey conducted in the United States, over 6 million women aged 15-44 reported impaired ability to get pregnant or carry a baby to term (Chandra et al., 2013). There are many causes of female infertility; however, the most common causes are problems with ovulation, fallopian tube obstruction (tubal factor infertility), endometriosis, and cervical or uterus abnormalities (Olmedo et al., 2001). Ovulation is the point in the female menstrual cycle when a mature egg is released from the ovary. After ovulation, the ovum travels to the fallopian tube where it may be fertilized by sperm (Unuane et al., 2011). Ovulatory disorder is a term that describes a group of

disorders in which ovulation fails to occur (anovulation) or occurs on an infrequent or irregular basis (oligo-ovulation) (Unuane et al., 2011). Ovulatory disorders are one of the leading causes of infertility with approximately 25% of female infertility reported cases (Olmedo et al., 2011). The most common conditions that affect ovulation include polycystic ovary syndrome (PCOS), hypothalamic dysfunction, and premature ovarian insufficiency (Olmedo et al., 2011; Unuane et al., 2011; Witchel et al., 2015). In the United States, PCOS is the leading cause of female infertility, affecting as many as 5 million women of reproductive age (CDC, 2021). PCOS is described as an excessive production of adrenal androgens, mainly testosterone (Witchel et al., 2015). This overproduction of androgens can be caused by the release of excessive luteinizing hormone by the pituitary gland, high levels of insulin in the blood, or reduced levels of sex hormone binding globulin (SHBG), resulting in increased free androgens (Witchel et al., 2015). High levels of androgens affect the development and release of eggs from ovaries, causing irregular menstrual cycles and affecting the ability to get pregnant (Unuane et al., 2011).

Hypothalamic dysfunction can have a significant effect on ovulation, affecting female fertility. Hypothalamic dysfunction describes the altered production of the follicle-stimulating hormone (FSH) and the luteinizing hormone (LH) (Barbieri, 2019). Under the influence of gonadotropin releasing hormone (GnRH), the FSH and LH are produced in the pituitary gland and are responsible for stimulating ovulation each month during the menstrual cycle (Carson & Kallen, 2021). Excessive physical activity or emotional stress, a very high or low body weight, or a recent substantial weight loss can disrupt FSH and LH hormones, subsequently affecting ovulation.

Premature (primary) ovarian insufficiency (POI), also known as premature ovarian failure, occurs when the woman's ovaries stop producing eggs before the age 40 (Welt, 2008). In most POI cases, the exact pathophysiology is unknown, but research has shown it is most likely related to follicle issues (Lavin, 2016). Follicles are small sacs within the ovaries where eggs grow and mature (Welt, 2008). POI can be a result of follicles not functioning properly or follicles are depleted before menopause and may be caused by some genetic disorders, toxins (radiation or chemotherapy), or autoimmune disorders (Lavin, 2016; Welt, 2008). Only 1.4% of African American women have been diagnosed with POI. Although a very rare disease, only 5% of women with POI can conceive spontaneously (Chon et al., 2021).

Tubal factor infertility is defined as infertility caused by obstruction, damage, scarring, or disease of the fallopian tubes. These conditions can cause infertility by preventing the fertilization of an egg or preventing a fertilized egg from traveling to the uterus for pregnancy. Tubal factor infertility accounts for approximately 25% of female infertility cases in the United States (Tsevat et al., 2017). The most common cause of tubal factor infertility is infection. Sexually transmitted infections (STIs), most commonly chlamydia and gonorrhea, can cause damage and blockage to the fallopian tubes (Tsevat et al., 2017). If left untreated, STIs can lead to pelvic inflammatory disease (PID), which can severely damage the cervix, uterus, fallopian tubes, or ovaries and can potentially lead to infertility (Mitchell & Prabhu, 2013).

Endometriosis is the process in which the endometrial cells are moved from the uterine cavity during menstruation and subsequently become implanted in the pelvis outside of the uterine cavity (Symons et al., 2018). This leads to pelvic anatomy

distortion and inflammation that may affect fertilization, sperm, and oocyte function (Macer & Taylor, 2012; Saha et al., 2015). Approximately 40% of women with infertility are also diagnosed with endometriosis and approximately 15% of cases of infertility are solely related to endometriosis (Saha et al., 2015). Although the specific cause of endometriosis is not known, it is widely associated with chronic inflammation and extremely high estrogen levels (Macer & Taylor, 2012).

Unusual shaped uterus, cervical stenosis, and uterine fibroids are among several uterine or cervical abnormalities that can cause infertility (Olmedo et al., 2001). The most common uterine abnormalities leading to infertility are uterine fibroids (Desai & Patel, 2011). Uterine fibroids (leiomyoma) are benign polyps or tumors that depending on location can block fallopian tubes or obstruct implantation, affecting fertility (Guo & Segars, 2012). Fibroids affect approximately 35-77% of reproductive age-women and may be the sole cause of infertility in five percent of women (Desai & Patel, 2011).

African American women bear a greater risk for infertility related to tubal and uterine issues due to their increased risk of STIs and uterine fibroids. The current literature persistently indicates the racial disparity in STI prevalence among African American men and women (Prather et al., 2018). African Americans are more likely to be diagnosed with a variety of STIs including HIV, syphilis, chlamydia, and gonorrhea (Oser et al., 2017). Additionally, African American women are generally less likely to utilize health services and are disproportionately more likely to delay seeking health services when compared to White women (Smith et al., 2012; Wright et al., 2010). This further increases African American women's risk for potential consequences of untreated STIs, which includes pelvic inflammatory disease (PID) and infertility (Oser et al., 2017).

African American women have three times the risk of fibroids as White women (Eltoukhi et al., 2014). Uterine fibroids disproportionally affect African American women more because the fibroids develop at an earlier age, grow faster, and are larger, causing more severe symptoms (Stewart et al., 2013). There are also several potential risk factors that make African American women more likely to develop uterine fibroids but have not been exclusively proven to cause fibroids (Eltoukhi et al., 2014). These factors include obesity, stress, starting menstruation at an earlier age, and having lower Vitamin D levels (Stewart et al., 2013). Additional research is needed to understand why African American women develop fibroids more frequently and with more severity.

Fertility Knowledge and Beliefs

When assessing women's knowledge related to fertility and risks for infertility, their knowledge level is poor (Bunting et al., 2013). Previous studies have shown that generally, women are unaware of the biological aspects of conception, age of fertility decline, disease related infertility, specific risk factors for infertility, and the prevalence of infertility within the general population (Bunting et al., 2013). Because of lack of knowledge, misconceptions about fertility and infertility are often believed such as underestimating infertility rates, thinking infertility is only a female issue, and overestimating fertility treatment success rates (Kessler et al., 2013). This makes it difficult for women to understand the potential risks for infertility they could have and increase reluctance to seek help for infertility if warranted. Although fertility knowledge and beliefs have been studied, there are few studies that include adequate representation of African American women. Because of their increased rate of infertility and lack of

seeking help, it is important to understand how their fertility knowledge and beliefs may impact African American women seeking help for infertility.

Infertility Services and Utilization

According to NSFG, between 2011-2015, nearly 12% (7.3 million) women of childbearing age received infertility services (Pal, 2018). Infertility services include medical advice from health care professionals, help to prevent miscarriage, diagnostic testing, ovulation drugs, artificial insemination, in vitro fertilization or other assisted reproduction, and surgery for endometriosis or fibroids (Janitz et al., 2019; Pal, 2018). Of the various infertility service options, medical advice from health care professionals is the most utilized service (Pal, 2018). Racial disparities in infertility service utilization exist in the United States. African American women are 80% more likely to report infertility than White women and are 20% less likely to seek or receive infertility care (Dieke et al., 2017). Disparities in infertility service utilization are often attributed to cost, however some studies have suggested that cultural factors may play a significant role (Thoma et al., 2021). Infertility stigma, perceived bias from providers, and fear of disappointing a partner have been identified as cultural factors that may contribute to disparities in infertility service utilization (Dieke et al., 2017).

Infertility Help-Seeking

Infertility help-seeking focuses on the decision to seek or not seek infertility services (White et al., 2006). Studies have shown that many women who are unable to get pregnant do not seek help for infertility (Boivin et al., 2007). Understanding the reasons

why women decide to seek or not seek help for infertility remains unclear. Because infertility services are often associated with being financially and psychologically exhausting, women may not seek help when needed (Hasanpoor-Azghdy et al., 2014). However, there are many other factors to consider when attempting to understand infertility help-seeking behavior. The pursuit to or not to seek help for infertility may also be influenced by inequalities in income and health insurance, health care professional bias, cultural barriers, and a woman's individual beliefs and attitudes toward infertility services (White et al, 2006). Having an understanding of infertility help-seeking should be an important part of the national effort to confront racial and ethnic disparities in infertility service utilization.

Infertility Stigma

Stigma involves negative attitudes or discrimination against someone based on a characteristic or health condition that is outside the socially defined norm (Dovidio et al., 2000). Infertility stigma is defined as having a negative perception or feeling about the inability to have children (Whiteford & Gonzalez, 1995). This stigma can be from a societal aspect (how society views infertility) or from an individual aspect (how an individual experiencing infertility views infertility). The sociocultural construct of fertility originates from the importance of procreation to individuals and societies (Patel et al., 2018). The current literature suggests that developed nations and societies favor social marriage and childbearing (Patel et al., 2018). In most cultures and societies including the United States, motherhood is highly valued as a life-accomplishment and an important source of fulfillment and happiness (Benza & Liamputtong, 2014). If able,

most women adhere to the cultural and societal shaped desire to have children; the inability to have children may seem abnormal (Patel et al., 2018). Because of this, women experiencing infertility may feel shame and guilt for not being able to have children. Women experiencing infertility report feelings of tension, helplessness, hostility, anxiety, anger, social isolation, and frustration because of the stigma associated with infertility and has limited some women's decision to seek help (Dube et al., 2021; Johnson & Johnson, 2009; Taebi et al., 2021).

Along with societal and cultural factors, there are religious factors that contribute to infertility stigma. While faith communities are described as places to find resources, support, and healing, for women experiencing infertility, the communities can also be seen as a burden or source of strain (Greil et al., 2010; Paulsen, 2020). This may be attributed to the historical religious philosophy related to a woman's role as a mother. In some religions, it is important for women to have children and women may feel infertility is a consequence of wrongdoing or punishment from God (Roudsari et al., 2007). This may lead to women feeling condemned and guilty for not being able to get pregnant even though the cause of the infertility may be male factor or unknown (Greil et al., 2010). Previous research has shown that women with infertility reported feeling upset and offended when their pastor or priest lacked sensitivity to their struggle with infertility or were not equipped to answer questions (Rooney & Domar, 2018). In a previous study, women reported increased negative feelings regarding their infertility when unable to find support from spiritual leaders, which created feelings of isolation from their church (Paulsen, 2020). Some religions, such as Protestantism, Catholicism, Judaism, and Islam, also have specific views on different aspects of fertility treatments (Paulsen, 2020). For

those women, adhering to their religious traditions may create negative views on infertility and create dilemmas when deciding to seek treatment.

For African American women, cultural and spiritual factors may intensify infertility stigma. Cultural myths and misconceptions regarding fertility can affect feelings about infertility. With high rates of teenage pregnancy and unwanted pregnancies, these rates can be misleading and are interpreted as African American women do not have fertility issues (Parchment, 2019). Historically, African American women are culturally stereotyped as hyper-fertile, which leads to an assumption that infertility is not a health concern (Parchment, 2019). These assumptions are harmful to African American women by potentially minimizing the risk African American women have for infertility while also creating negative thoughts about infertility (Ceballo et al., 2015). Additionally, cultural myths about African American women's strength and ability to overcome challenges and the cultural expectation to maintain privacy further contribute to infertility stigma and may impede infertility help-seeking (Ceballo et al., 2015; Missimer et al., 2011).

The spiritual and religious aspect of African American culture increases the shame and failure African American women feel when unable to conceive (Ceballo et al., 2015). In the African American culture, most people look to their faith for support or information when struggling with a health condition (Ward et al., 2009). With infertility, this cultural norm is no different. Because infertility is a highly stigmatized condition among African Americans, there is less knowledge and acceptance of infertility which may lead to pastors and church members not providing women experiencing infertility with the best advice (Ceballo et al., 2015). Instead of directing women to seek help,

people within the church community may question the faith of women who seek help for infertility because they are not solely relying on their spiritual faith to conceive a child (Ceballo et al., 2015). This further creates isolation from social environments that should be a source of positive support when suffering with infertility.

Summary

Infertility is a major life crisis affecting millions of men and women around the world (Pal, 2018). With advancements of infertility research including diagnosis and treatment, disparities remain in infertility help-seeking among African American women. Studies have examined infertility help-seeking but not adequately within the African American population. White women of high socio-economic and educational status are the most common demographic characteristics among studies exploring infertility help-seeking. This excludes many minority groups, specifically African American women, who experience infertility at twice the rate as White women (Cerbert-Gaitors et al., 2022; Chin et al., 2015; Wiltshire et al., 2019). Additionally, previous studies recruit participants from fertility clinics, which excludes women who have not sought help. This limits the understanding of infertility help-seeking to only the perspective of women who seek help and not those who do not seek help. Having the perspective of women who did not seek help will allow a deeper understanding of their decision to not seek help and identify barriers that may have impacted this decision.

Search Strategy

A review of literature was conducted to evaluate the current literature of the variables of interest. PubMed, PsycInfo, Embase, and CINAHL were used to search for English written, full text journals using combinations of keywords. Keywords for this search included fertility, infertility, and help-seeking. Because of the limited number of studies and that the nature of the problem is not widely studied among the population of interest (African American women), publications were not excluded due to a specific publication date timeframe or racial/ethnic group. PubMed generated 24 articles, CINAHL generated 45 articles, Embase generated 92 articles, and PsycInfo generated 33 articles. Duplicates were removed (n = 20), leaving 174 articles. After a review of titles and abstracts, 110 articles were excluded. Articles were further screened by examining for full text availability, which left 45 articles for full review. After full-text review, 33 articles were selected for this review of literature. Appendix A illustrates the literature search strategy. The findings from this literature review synthesized the relevant literature related to infertility help-seeking and related concepts.

Analysis of Literature

This integrative review of the literature presented what is known and not known about infertility help-seeking and related concepts (fertility knowledge, fertility beliefs, infertility service utilization). Current gaps in the literature were identified to support the need for this study. The infertility help-seeking literature was presented in four components: recognizing infertility as a problem, attitudes and beliefs towards treatments, sociodemographic variables, and sociocultural factors.

Fertility Knowledge

Fertility knowledge refers to knowledge about fertility and infertility in childbearing age women (15-44) (Swift & Liu, 2014). Studies have shown that childbearing age women have minimal fertility knowledge. Bunting et al. (2013) showed an association between sociodemographic factors, high education level, and high income with increased fertility knowledge. A lack of fertility knowledge may increase the duration of infertility among women before they decide to seek help (Shreffler et al., 2017).

Fertility Knowledge Related to Ovulation and Fertility Decline

The current literature suggests that fertility knowledge related to ovulation and fertility decline is low (Hashiloni-Dolev et al., 2011; Mu et al., 2019; Peterson et al., 2012; Virtala et al., 2011). There is a general understanding regarding conception and contraception use, however specific knowledge regarding optimal fertility age, age of fertility decline, and identifying the ovulation period during the menstrual cycle is low (Mu et al., 2019). Previous studies suggest women can define ovulation but are unable to provide accurate information on when ovulation occurs during a menstrual cycle (Hampton & Mazza, 2015; Mu et al., 2019). Most women are unable to correctly identify the fertile period (ovulation) of the menstrual cycle and are unaware that a normal menstrual cycle can vary between 25 and 35 days and that ovulation, although generally occurring 14 days before menses, may not occur at that time (Hampton & Mazza, 2015; Lundsberg et al., 2014).

Several studies have shown the overestimation of the window of fertility and age of fertility decline (Hashiloni-Dolev et al., 2011; Mu et al., 2019; Peterson et al., 2012). This review also identified a misconception among women that a woman's fertility remains consistent from the age of puberty to age of menopause (Mu et al., 2019). Young women (age 18-24) were more likely to understand the risks and complications associated with advanced age pregnancy such as miscarriage or genetic abnormalities to the baby. However, they were less likely to recognize that the chance of conceiving significantly decreases at an older maternal age (Lundsberg et al., 2014). The current literature suggests that most women understand that age has an effect on fertility, however they still overestimate the chance of conceiving at the age of 35 or older (Hashiloni-Doev et al., 2011; Sabarre et al.,2013; Virtala et al., 2011). Previous studies suggest that women of childbearing age assume fertility does not begin to decline until after the age of 40 (Virtala et al., 2011). This warrants concern because according to the American College of Obstetricians and Gynecologists (ACOG), female fertility begins to decrease approximately at age 32 and more rapidly decreases after age 37 (ACOG, 2014).

Fertility Knowledge Related to STI History and Uterine Fibroids

Infertility related to tubal factors has been highly linked to untreated sexually transmitted infections that cause tubal inflammation, damage and scarring (Tsevat et al., 2017). The most common sexually transmitted infections causing this type of infertility are *Chlamydia trachomatis* and *Neisseria gonorrhea.* African American women have a higher prevalence of *Chlamydia trachomatis* and *Neisseria gonorrhea* than White women (Gonullu et al., 2021). When assessing fertility knowledge, women do not consistently

list STI history as a fertility risk factor (Alexander et al., 2019; Lundsberg et al., 2013; Sabarre et al., 2013). Women of childbearing age are more likely to identify maternal age and lifestyle factors such as substance abuse and smoking as fertility risk factors than to identify STI history (Sabarre et al., 2013). A recent study investigating the impact of STI history on fertility knowledge among urban African American adolescents and young adults revealed that the male participants had a greater understanding of the relationship between certain STIs (chlamydia and gonorrhea) and fertility issues than the female participants (Alexander et al., 2019).

Uterine fibroids, or leiomyoma, are non-cancerous tumors of the uterus that may cause severe pain, bleeding, and infertility (Guo & Segars, 2012). Fibroids affect approximately 35-77% of reproductive-age women and may be the sole cause of infertility in 1-2.4% (Desai & Patel, 2011). Only one study identified in this review assessed women's knowledge of the impact of fibroids on fertility. A little over half of the participants believed fibroids could affect childbearing and approximately 30% of participants believed fibroids could cause infertility (Adegbesan-Omilabu et al., 2014). This aligns with the current literature which suggests women do not generally associate painful menses and irregular menstrual bleeding as risk factors for infertility (Lundsberg et al., 2014). This raises concern as African American women have increased rates of infertility related to uterine fibroids.

Fertility Treatment Knowledge

This review of literature suggests that fertility knowledge regarding fertility treatments among women is minimal. Previous studies reported that women do not have

accurate information regarding assisted reproductive technologies (ART) because of their overestimation of ART birth rates and chances of first attempt success (Hashiloni-Dolev et al., 2011; Peterson et al., 2012). Overestimation of treatment success rates could affect the timing of childbearing efforts by assuming success rates would be the same if childbearing is delayed to an older reproductive age (Bunting et al, 2013). This is a common misconception among women that ARTs can be successful despite the age-related decline in fertility (Daniluk et al., 2012; Peterson et al., 2012). Although women have some knowledge of the different ART options, they are often unaware of their complication rates (Kudesia et al., 2017). Gossett, Nayak, Bhatt, and Bailey (2013) revealed that most women knew that fertility treatments are associated with multiple gestations but were less aware that they can increase risk for complications such as miscarriages, stillbirths, fetal deaths, and complications during pregnancy.

Fertility Beliefs

The Role and Value of Motherhood Among African American Women

The sociocultural construct of fertility originates from the importance of procreation to individuals and societies (Patel et al., 2018). The current literature suggests a common theme among developed nations and societies, which is the favorable social setting of marriage and childbearing (Patel et al., 2018). For instance, in most cultures and societies, motherhood is highly valued as a life-accomplishment as well as an important source of fulfillment and happiness (Benza & Liamputtong, 2014). However, the old traditional views and themes of motherhood cannot always be applied to the beliefs and experiences of African American women or any other minority group

(Ceballo et al., 2015). Unlike the old traditional views of women working in the home, currently, more women are also in the work force and seeking educational and career advancement which has altered how society views the role of motherhood. However, most women still value being able to have children and still want to have children (Benza & Liamputtong, 2014). A previous study interviewing 50 African American women revealed that 32% of the participants expressed beliefs that motherhood equated to womanhood and that childbearing was very important (Ceballo et al., 2015).

Generally, African Americans are more likely to endure negative health outcomes due to the effect of social determinants of health related to race, social class, and economic status (Mosher et al., 2012). In the case of fertility beliefs, these concepts may influence how African American women feel about motherhood and childbearing (Mosher et al., 2012).

Perceived Social Support

Social support has also been linked to shaping fertility beliefs. Social support has been shown to influence women's beliefs regarding their fertility intentions and can help weaken the negative attitudes regarding childbearing because of economic instability (Bernardi & Klarner, 2014). Support from partners, family, and friends can help mold women's fertility desires and help regulate changes in attitudes regarding new family patterns, such as the acceptability of having fewer children, adoption, delayed childbearing, or voluntary childlessness (Bernardi & Klarner, 2014). Sources of social support can be emotional, informational, and instrumental (tangible resources). Women

who have social support are more likely to have positive attitudes or beliefs regarding their fertility and future childbearing (Begun et al., 2020).

Cultural Misconceptions and the Stigma of Infertility

Cultural myths and misconceptions regarding fertility can affect fertility beliefs. With high rates of teenage pregnancy and unwanted pregnancies, these rates can be misleading and interpreted as African American women do not have fertility issues (Parchment, 2019). In fact, studies suggest that African American women may be twice as likely as white women to have fertility problems but are less likely to seek medical help (Ibrahim & Zore, 2020). Historically, African American women are culturally stereotyped as hyper-fertile, which leads to an assumption that infertility is not a health concern (Parchment, 2019). This assumption is harmful to African American women by potentially minimizing the risk African American women have for infertility (Ceballo et al., 2015). This misconception can also lead to doctors internalizing the stereotype, which could delay referrals to reproductive specialists, medical researchers, and resources for this population (Parchment, 2019). This misconception has also been associated with creating negative beliefs towards fertility treatments, warranting inaction in infertility help-seeking (Wellons et al., 2008).

Infertility Stigma

Infertility stigma is a concept linked to causing various levels of psychological and social strain for both men and women but especially for women (Taebi et al., 2021). Infertility stigma is associated with feelings of shame and guilt, often leaving an

individual feeling socially isolated (White et al., 2006). Women experiencing infertility report feelings of tension, helplessness, hostility, anxiety, anger, and frustration because of the stigma associated with infertility, which has limited some women's decision to seek help (Johnson & Johnson, 2009). A study revealed that for African American women, infertility stigma often leads to suffering with infertility in silence because of the negative impact on their self-esteem (Taebi et al., 2021). African American women are not often included in the social images of infertility and are not extensively seen in fertility clinics seeking help (Wellons et al., 2008). Studies have reported that the lack of representation of African American women experiencing infertility creates feelings of being abnormal because they do not see other women like themselves (Dimitriadis et al., 2017). Additionally, a previous study revealed that the spiritual and religious aspect of African American culture increases the shame and failure that African American women feel when unable to conceive (Ceballo et al., 2015).

Infertility Services and Utilization

Nearly 7 million women of childbearing age (15 – 44) in the United States reported using infertility services (ASRM, 2012). Infertility services include advice from a physician (counseling), diagnostic testing, drugs to improve ovulation, artificial insemination, in vitro fertilization, or surgery or drug treatment for certain disorders that may affect reproduction (endometriosis, uterine fibroids, etc.) (Kessler et al., 2013). Counseling is the least invasive intervention, which includes providing information to optimize chances of natural conception and providing information regarding other potential options. In vitro fertilization (IVF) is more invasive but has a high pregnancy

rate with a lower risk for multiple gestations compared with other treatments (Chin et al., 2015). This review of literature was only able to identify articles that only reported infertility service utilization from the National Survey of Family Growth (NSFG), which is conducted by the National Center for Health Statistics. According to a secondary analysis of the most recent cycles of the NSFG survey, of the 12, 456 women that participated in the study, 15% of women sought infertility services with over 8% stating it would be difficult to have a child but had not used infertility services (Thakker et al., 2021). The most reported service used was counseling and ovulation drug therapy. The least reported services used were in vitro fertilization and reproductive surgery. Infertility service utilization was most common among women who identified as White, married, high level of education and income, and had insurance (ASRM et al., 2015; Thakker et al., 2021). One additional study reported higher infertility service utilization was accessed by women with a college degree, income above $100,000, insured, and who were U.S. citizens when compared with women with less than a high school diploma, income less than $25,000, uninsured, and non-U.S. citizen (Galic et al., 2020).

Infertility Service Utilization Disparities

There is evidence that despite having higher rates of infertility, minority groups such as African American and Hispanic women are less likely to use infertility services than White women (Insogna & Ginsburg, 2018). According to an analysis of the NSFG's data, 12% of White women ages 35 – 44 reported having used some type of infertility service compared with 3% of African American and 5% of Hispanics (Chin et al., 2015). In examining infertility service utilization disparities related to racial differences, studies

have shown that African American women wait longer to undergo infertility services compared with White women (Seifer et al., 2008). Previous studies have identified symptom recognition, education level, level of fertility knowledge, insurance status, cost, and access to care as contributing factors to the infertility service utilization disparity between minorities and White women (Chandra et al., 2005; White et al., 2006). The current literature suggests that while it is difficult to separate the potential variables that create disparities in the use of infertility services, the cost of infertility services is the most used variable to explain the inequities in infertility service utilization (Kessler et al., 2014). Despite expanded insurance coverage of ARTs, including IVF, only 24% of the ART demand in the United States is met (Chambers et al., 2009). On average, one cycle of IVF, which is one of the most expensive infertility services, can cost approximately $19,000 and in most cases are not covered by insurance (ASRM, 2015). With the average household income in the United States being approximately $70,000, ART may not be financially feasible to many women who need it (Guzman, 2019). In Massachusetts and Illinois, where it is mandated that infertility services are covered by insurance, studies revealed that disparities in access to infertility services persisted (Jain & Hornstein, 2005; Missmer et al., 2011). Studies revealed that African American women still reported barriers to treatment related to race, income, getting appointments, taking time from work, and body mass index (BMI) (Galic et al., 2021). This suggests despite providing insurance coverage for infertility services, additional qualitative research is needed to explore the complex social, cultural, and racial factors that create difficulty for African American women to receive infertility care to understand and address these barriers.

Infertility Help-Seeking

Because of the increasing demand and need for infertility services, infertility help-seeking is a multifaceted concept that is needing attention. Despite growth in women seeking infertility services, there is still a large proportion of women who do not seek help. In the United States less than half of women with infertility seek help (White et al., 2006). This is far less compared to other countries such as Finland, the Netherlands, and Britain with approximately 60%–85% of women with infertility seeking help (Datta et al., 2016; White et al., 2006).

Factors Influencing Infertility Help-Seeking

While women may want to have a child, in cases of having difficulty getting pregnant, some women may still not seek help for different reasons. Help-seeking for any medical condition may come at high cost, financially, psychologically, and physically. This is no different in the case of infertility. Because infertility is a complex socially constructed phenomena that cannot always be successfully treated, there are a range of factors to consider in understanding infertility help-seeking.

Recognizing Infertility as a Problem

For help-seeking in any condition or disease, the theory is that people must recognize a problem to seek help (Shaw, 2001). For infertility, this may be difficult to recognize especially if a woman is not knowledgeable of issues that may cause a fertility issue (abnormal menstruation, etc.) (White et al., 2006). Women having fertility issues may attribute problems conceiving with stress or mistiming of intercourse, and not realize

their issue may be more serious (Greil & McQuillan, 2004). Also, couples may have unprotected sex for over a year without getting pregnant, but not realize this could be a potential issue if they are not actively attempting pregnancy (Johnson & Johnson, 2009). Research has shown that women who are trying to conceive are more likely to seek help compared with those who are not actively pursuing pregnancy (Greil & McQuillan, 2004). This may be related to the lack of fertility knowledge or fertility beliefs that do not alarm women to be concerned about fertility issues despite attempting to or not to conceive.

Attitudes and Beliefs Towards Treatments

Infertility help-seeking may be influenced by beliefs towards infertility services, especially if such beliefs prevent women from seeking help (Greil & McQuillan, 2004). Previous studies of infertility help-seeking suggest that women who have positive attitudes and beliefs towards medical science will be more likely to seek treatment than their counterparts with more negative attitudes (Slauson-Blevins, 2011). Negative beliefs related to the safety, accessibility, and cost of infertility services have been associated with limiting the likelihood of infertility help-seeking (Bunting et al., 2013; Thoma et al., 2021). In a previous study examining treatment discontinuation, 25% of participants discontinued treatment because of negative treatment attitudes while 70% of these participants dropped out before undergoing any treatments (Brandes et al., 2009). Infertility help-seeking may be avoided because of negative beliefs of complications or treatments not being successful causing more stress. Additionally, being overly optimistic of infertility treatment success rates can also affect infertility help-seeking as this may

delay women seeking timely help, assuming treatments can reverse effects of delayed childbearing (Bunting et al., 2013). Belief and attitudes towards treatments have shown to be an important consideration when deciding to seek or not seek help for infertility (Boivin et al., 2007; White et al., 2006).

Sociodemographic Variables

Because the cost of infertility services is the most identifiable factor to utilization, socioeconomic status is a factor that may influence infertility help-seeking. Women with lower levels of education and occupational status are less likely to seek help for infertility (Datta et al., 2016; White et al., 2006). A study assessing infertility help-seeking in Michigan reported that 80% of women with college degrees or higher sought help and only approximately 30% of women with a high school degree sought help (Ceballo et al., 2015). Additionally, over 60% of women with an income greater than $100,000 sought help compared to 30% of women with household income $25,000 or less (Ceballo et al., 2015). Most infertility services are delivered in private sectors, which limits access only to individuals of high socioeconomic status and with insurance coverage (Tavares et al., 2016). The current literature suggests that a greater portion of African American women are either uninsured or covered by government policies (i.e., Medicaid) compared with White women (Sohn et al., 2017). This is reflected in a study where African American women who were insured by Medicaid or uninsured did not seek help for infertility at the same rate as White women with private insurance (Wiltshire et al., 2019). However, a study assessing infertility help-seeking among African American and Hispanic women with private insurance still reported these women are less likely to seek help when

compared with White women, suggesting there are additional factors affect infertility help-seeking in this population (Chin et al., 2015).

Age

Previous studies reported that women of older age are more likely to seek help than women of earlier age (Oakley et al*.,* 2008; Wilkes et al., 2009). This may be attributed to being more aware of an issue or because of the latest trend of delayed childbearing. In one particular study, infertility help-seeking was highest among women who became mothers at 35 or older compared with women less than 35 (Datta et al., 2016).

Race

White women are twice as likely to seek help for infertility compared with African American women (Greil & McQuillan, 2004). In a recent study, African American women reported barriers to seeking help for infertility were related to difficulty getting appointments, taking time off work, and affording infertility services (Galic et al., 2021).

Sociocultural Factors

Fertility desires and intentions are strong indicators to help-seeking behavior. Although the majority of infertility research focuses on the woman, it is important to acknowledge the desires and intentions of both partners. The current literature suggests that a couple's want or intentions to have a child prompts engagement with help-seeking

behavior. However, these wants, and intentions may change based on life circumstances. Partners may began to have different childbearing desires, which affects help-seeking (Johnson & Johnson, 2009). This would suggest that couples with similar fertility desires and intentions are more likely to seek help for infertility than couples who do not share similar fertility desires and intentions (Johnson & Johnson, 2009).

As mentioned earlier, the role of motherhood or parenthood holds an important role in infertility help-seeking. The current literature suggests that many women hold great value in fulfilling the social role of being a mother (White et al., 2006). Researchers hypothesize that the greater value of motherhood to a woman, the more likely she is to address signs of difficulty becoming pregnant and seeking help (White et al., 2006).

Social Support

Social support has been reported to affect infertility help-seeking. Social support has been widely studied in various conditions and has been identified as a coping resource, buffer when dealing with a stressful situation, and being a factor in how people make medical decisions (Slauson-Blevins, 2011). Social support can include support from partner, friends and family, and health care professionals (Slauson-Blevins, 2011). Support from a spouse or partner plays an important role in the decision to seek help for infertility. A previous study found that some women would prefer to discuss infertility service options only with their partner before discussing with physicians (Johnson & Johnson, 2009). In one study, African American women reported disappointing a spouse was a concern when deciding to seek help for infertility (Missmer et al., 2011). Because infertility is a stigmatized condition, people experiencing infertility are not always

comfortable disclosing their infertility status to others. Therefore, the relationship and support from the partner is valuable in the process in deciding to seek or not seek help.

Additionally, support from family and friends may also influence infertility help-seeking. The current literature regarding family and friend support remains mixed as a common theme among women experiencing infertility is to suffer in silence. In one particular study, African American women were more likely to report concern about friends and family finding out about their fertility status and seeking help, which suggests there is a lack of support for infertility help-seeking in their social network (Missmer et al., 2011). However, other studies have found that women who consider having a positive social circle often asked for advice from female family members and peers when considering seeking help for fertility issues (Johnson & Johnson, 2009).

Although women report not receiving great support from health care professionals, women value their opinions and recommendations when seeking help (Slauson-Blevins, 2011). Previous studies have shown that women who sought help for infertility were often critical of health care professionals because they were not provided informational support, felt rushed, or did not receive any support at all (Malin et al., 2001). This is supported by health care professionals being a major factor as to why women do not seek help or discontinue treatments before completion (Gameiro et al., 2012). In contrast, women who reported having positive encounters with healthcare professionals stated healthcare professionals were supportive and individualized their treatment encounters (Malin et al., 2001).

Infertility Stigma

The current literature on help seeking for stigmatized conditions suggest that stigma will deter people from admitting there is a problem, seeking help, and following recommended treatments (Slauson-Blevins, 2011). Previous research suggests that people are less likely to discuss stigmatized conditions with others and will not seek help unless symptoms overshadow the perceive risks of seeking help (Shaw et al., 2001). It has been reported that infertile women who did not seek help for infertility did not seek help because of fear of being giving a stigmatized label (Bunting & Boivin, 2007). This is more common in African American women because they report more concern about social stigmatization than White women (Missmer et al., 2011). Research has found that African American women's beliefs and experiences with stigma in medical settings were barriers to accessing and receiving quality care (Prather et al., 2018). African American women have reported higher stress levels related to infertility stigma than White women (Greil et al., 2011). African American women who were considered infertile reported high levels of stigma and moderate stress than African American who were fertile (Ozturk et al., 2020). This may be a critical factor in why African American women are less likely to seek help for infertility than White women.

Summary

This integrative review of the literature presented what is known and not known about infertility help-seeking and associated concepts. The literature was presented in three main concepts: infertility, infertility service utilization, and infertility help-seeking. Factors influencing infertility help-seeking literature was discussed in four main

components: recognizing infertility as a problem, beliefs towards treatments, sociodemographic variables, and sociocultural factors. The current literature reflects that these factors affect infertility help-seeking. However, how these factors influence African American women's infertility help-seeking remains unclear. African American women were marginally reflected in some of the studies, but still remain underrepresented within the sample populations. Much of the infertility literature is conducted in fertility clinics only providing information from women seeking help for infertility. This does not support providing adequate information for African American women as they are less likely to seek help or delay seeking help. Additionally, most of the research is conducted within fertility clinic reflecting only experiences of women seeking help and do not capture the experiences of women who do not seek care. This exclusion limits understanding what prohibits women from seeking help for infertility. The literature suggests that studies regarding infertility help-seeking should move to a more comprehensive approach that would explain or better describe the disparities African American women face with infertility service utilization and identify areas needed to improve infertility help-seeking among this population.

Theoretical Framework

Theoretical or conceptual frameworks are used to guide and provide rationale for investigating a research problem. The Traits-Desires-Intentions-Behavior (TDIB) model is a framework used to describe reproductive decision making. This framework was used to guide this study in understanding infertility help-seeking among African American women.

The TDIB model was developed to describe fertility related decision-making by assessing reproductive motivations and behaviors (Miller, 1994). The model includes a four-step process that starts with motivational traits that interact with the cognitive constructs of desire and intention and in turn these factors contribute to reproductive behavior (Wagner et al., 2014). According to the TDIB model, a woman's perceived fertility desires are the main source of her fertility intentions, which are likely to explain a subsequent reproductive behavior (Miller, 1994). Miller (1994) explains that motivational traits are people's dispositions to respond in specific ways under certain conditions. Motivational traits for fertility may include age, race, ethnicity, fertility beliefs, religion, level of education, income, family support, level of fertility knowledge, and social norms.

The second step of this process is the development of desires. In this step, traits that are psychologically relevant to a specific behavior combine to produce a state of desire (Miller, 1994). Wanting to achieve a goal through action represents the desire concept of the TDIB model. This could be expressed through a woman wanting or not wanting to have a child or a woman wanting to seek help for infertility to have a child. Fertility desires may be affected by personal values and social constructs (Miller, 1994). Desires represent what a woman would prefer while also evaluating the positive or negative consequences of that decision.

Intentions are psychological states that represent what someone actually plans to do (Miller, 1994). Desires become intentions when what one wants to do is to be achieved. Miller (1994) states that intentions can be influenced by the desires and attitudes of others to include spouses, family members, or people within a woman's social network. Fertility intentions signify an individual's or couple's family planning

(Mencarini et al., 2015). Age, health and relationship status are considered major influences in fertility intentions. These influences can negatively or positively affect a woman's intentions in reproductive decision making (Luppi & Mencarinin, 2018).

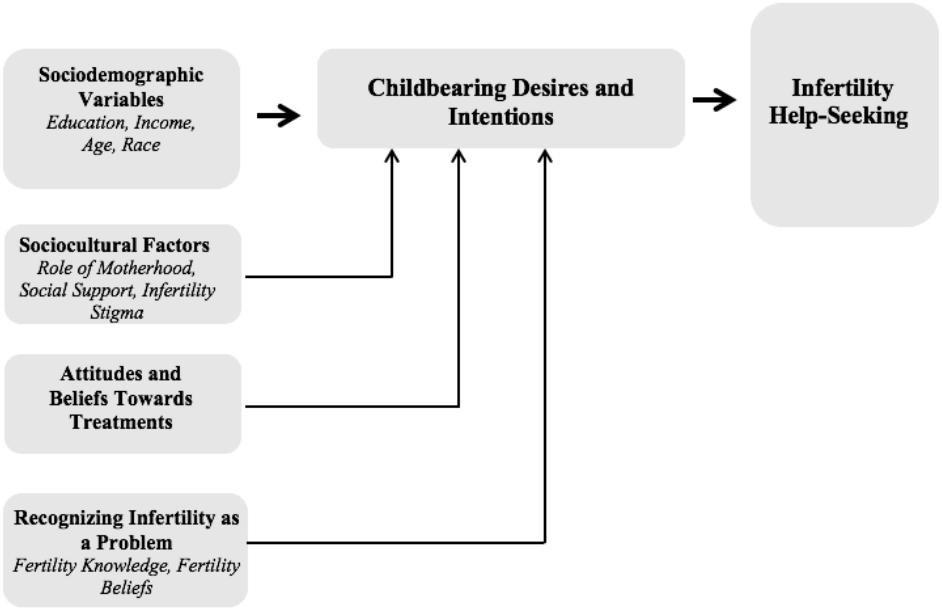
The psychological sequence of traits, desires, and intentions regulates and determines subsequent reproductive decision making and behaviors. In the TDIB framework, Miller classifies reproductive behaviors in three conception-oriented actions: trying to achieve conception (proception), trying to avoid conception (contraception), or trying not to do either of the two (Miller, 2011). Miller further explains those trying to achieve conception participate in sexual behaviors that improve their chances of conceiving. Proceptive behavior includes discontinuing contraception, increasing frequency of sexual intercourse, pinpointing ovulation period during a menstrual cycle, or seeking infertility services (Miller, 1994). Those avoiding conception participate in activities that reduce their chances of pregnancy, such as contraceptive use or sexual abstinence (Miller, 2011). For this study, we focused on behaviors that will facilitate proception, which include infertility help-seeking and the use of infertility services.

Figure 1

Traits-Desires-Intentions-Behavior Model

Figure 2

Modified Version of Traits-Desires-Intentions-Behavior Model



Summary

Many factors may influence infertility help-seeking among African American women. The Traits-Desires-Intentions-Behavior model has been used to explore the main predictors of reproductive decision making and reproductive behavior such as family support, sociocultural factors, age, education, religion, and partner's desires and intentions. For these reasons, the TDIB model was the most appropriate framework to guide this study seeking to understand the disparities African American women face with infertility service utilization and identify areas needed to improve infertility help-seeking among this population.

Ethical Considerations

This study was submitted to the University of Alabama at Birmingham (UAB) Institutional Review Board (IRB) for review and received approval. IRB approval ensures that the study plan met requirements for ethically sound research. After approval, recruitment and data collection began. Each participant was provided information regarding the study purpose and presented with an information sheet indicating all risks for participating in the study. Because the study was approved with exempt status, participants were not required to sign an informed consent. Participants received study information sheet and acknowledged all risk related to the study. Because the concepts of interest involved in this study may be considered sensitive or emotionally upsetting, participants were advised that they can stop participation at any time. Infertility and its treatment can affect all aspects of people's lives, which can cause various psychological-emotional disorders or consequences including turmoil, frustration, depression, anxiety, hopelessness, guilt, and feelings of worthlessness in life. It is a sensitive issue that can be difficult to discuss with family, friends, and strangers. Online resources for various fertility support groups and resources were shared with participants who needed support.

Privacy in research refers to protecting the individual's right to control access to their participation in a study (Polit & Beck, 2012). Conducting interviews in a private setting was a safeguard used to maintain participant privacy. Confidentiality in research refers to safeguarding the information that is provided by participants. Study participants remaining anonymous ensured participant's confidentiality was protected. Additionally, participant data were de-identified and kept on a password protected computer preventing unauthorized individuals from accessing the data. Individual participant information will

not be publicly reported or made accessible to anyone. Information on how personal information was stored was disclosed to participants during the informed consent process.

Summary

When conducting research using human subjects, ethical issues should be considered, and strategies should be in place to reduce risks. Providing study risks, protecting privacy and confidentiality are issues to consider when conducting qualitative research. Risks to participants were addressed prior to participants receiving any study material (demographic form, fertility knowledge survey). To reduce ethical and human subject issues, information sheets were provided, and study risks were acknowledged by participants, interviews were conducted in private settings, personal information was de-identified, and data were stored on a password protected computer.

Chapter Summary

Although advancements in infertility research and infertility treatments have happened, disparities remain in infertility help-seeking among African American women in the United States. The purpose of this chapter was to review and synthesize the current literature regarding infertility help-seeking and related concepts to guide the development of this qualitative study. This chapter described the concepts of interest, analyzed the literature of the concepts of interest, and discussed ethical issues for conducting the study. Understanding African American women's infertility help-seeking and the factors that influence it will be a critical first step towards developing education or interventions

to improve infertility service utilization and help achieve ideal reproductive outcomes in this population.

CHAPTER 3

METHODS

Infertility is defined as the inability to become pregnant or maintain pregnancy after attempting for one year or more (CDC, 2021). The Centers for Disease Control and Prevention (CDC) estimates that approximately 12% (more than 6 million) of women of childbearing age in the United States have difficulty conceiving or maintaining a pregnancy (CDC, 2021). Compared with White women, African American women are more likely to experience infertility (Wellons et al., 2008; Wiltshire et al., 2019). Despite this fact, African American women delay or do not seek infertility services at the same rate as White women (Wellons et al., 2008). As the cause of delaying or not seeking infertility services are attributed to many factors, it is not clear what factors influence or impede infertility help-seeking among African American women. Currently, there is only one research study specifically attempting to understand the infertility help-seeking of African American women (Ceibert-Gaitors et al., 2022). Additionally, there is no research exploring infertility help-seeking among AA women who do not seek treatment. Therefore, the study was aimed to fill the gap in knowledge in exploring factors that influence or impede infertility help-seeking among African American women.

Chapter One provided an introduction for this study including the problem statement, background and significance, the purpose of the study, theoretical framework, and important key terms. In Chapter Two, an integrative review of the literature was

conducted to evaluate the current literature regarding infertility help-seeking. Chapter Three will discuss the methodology of the study including the research design, sample, setting, informed consent process, data collection plan, strategies for ensuring rigor and credibility, and data analysis plan.

Study Aims

1. Describe the facilitators and barriers to infertility help-seeking among African American women.
2. Explore African American women's beliefs related to infertility and infertility services.
3. Investigate how African American women's fertility knowledge impacts infertility help-seeking.
4. Explore how infertility stigma impacts infertility help-seeking among African American women.

Research Questions

- What are the facilitators to infertility help-seeking among African American women?
- What are the barriers to infertility help-seeking among African American women?
- What are African American women's beliefs about infertility and infertility services?
- What role does fertility knowledge play in shaping infertility help-seeking in African American women?

- How much of a role does infertility stigma play in infertility help-seeking among African American women?

Design

The purpose of this qualitative study was to describe how African American women describe and understand the factors that influence their choice regarding the use of infertility services. A qualitative approach provides rich descriptions of complex or not clearly understood phenomena and promotes an understanding of how people conceptualize their own experiences, each other, and the social world (Holloway & Galvin, 2016). A qualitative descriptive design was chosen to provide responses that reflect how people describe a particular phenomenon and describe factors that facilitate or hinder a behavior. This study used qualitative description to draw insight on the factors that impact infertility help-seeking among African American women who are unable to become pregnant.

Sample and Setting

Snowball and criterion sampling are sampling strategies that were utilized for this study. After approval with the University of Alabama at Birmingham's Institutional Review Board (IRB), social media platforms (Facebook, Instagram, Twitter) and study flyers were used as recruitment methods for this study. Using social media sites to recruit for studies has become an innovative technique for recruiting, as it permits researchers to access a wider audience while keeping costs low and sustaining privacy (Gelinas et al., 2017). Additionally, recruitment through social media is effective in recruiting difficult-

to-identify participants or investigating stereotypical or stigmatizing research topics (sexual health, infertility, mental disorders, etc.) (Arigo et al., 2018). Recruitment flyers were developed to include the purpose of the study, eligibility criteria, and PI contact information. Flyers were publicly shared to the selected social media platforms and interested participants were able to contact the PI by phone or email to receive additional information. The PI requested that the administrators of African American fertility support groups share study information with group members. Other recruitment avenues included sending emails to leaders of African American community groups (sororities, book clubs, church groups, etc.) requesting them to share study information with members. The PI contacted community group leaders through their public social media websites, or by phone. Once participants were identified, they were also asked to invite other potential participants to be a part of the study. Once interest is expressed, potential participants were screened to ensure they met eligibility criteria. After participants were screened, the PI provided each participant with the study information sheet that discussed all study risks.

For qualitative research, the recommended sample size differs between textbooks, but an adequate sample size can range from 6 to 20 participants (Ellis, 2016). The sample size for this study was 15 or until data saturation was achieved. Criteria for selection of participants included: (a) participants were between 18 – 44 years of age; (b) identified as Black or African American; and (c) unable to achieve pregnancy despite attempting for at least 1 year. Participants were excluded if participants were experiencing secondary infertility (unable to become pregnant after previously being able to become pregnant). The exclusion of women experiencing secondary infertility was due to the recognition

that their experiences may significantly differ from those of women facing primary infertility.

Informed Consent

Once interest in participating in the study was expressed, participants were asked screening questions. Screening tools are used to determine if a participant is eligible to participate in the study. The screening tool included questions that directly correlated with the inclusion and exclusion criteria of the study. Participants that did not meet inclusion criteria, were not eligible to participate in the study.

After participants were screened, the PI provided all participants with the study information sheet. The study information sheet was approved by UAB's IRB. The study information sheet contained information pertaining to the study's purpose, how it would be conducted, the means to contact the principal investigator (PI), the benefits associated with participation, the potential risks involved, the methods for maintaining confidentiality, and the procedures for storing and reporting data. The information sheet was written at an 8th grade reading level and written in lay language. The study information sheet was emailed to all participants. To ensure that the participants understood the information presented, risk of participating in the study and the option to not be a part of the study were discussed with all participants prior to the beginning of the interview. Time was allotted for questions and participants were reminded they were under no obligation to participate in the study. Data collection began once participants acknowledged all the risks associated with their participation in the study and had all their questions addressed.

Data Collection

The data collection process consisted of three components: a demographic form, a quantitative instrument measuring fertility knowledge, and the interview. The demographic form, developed by the principal investigator (PI), included questions regarding age, gender, education, ethnicity, income, religious affiliation, insurance, and relationship status.

The instrument measuring fertility knowledge was adapted from the Cardiff Fertility Knowledge Scale (CFKS). The CFKS is a 13-item questionnaire evaluating fertility knowledge in three areas: indicators for reduced fertility, misconceptions about fertility and basic facts about infertility. The response scale includes "true," "false," or "don't know" responses. A correct answer was assigned as 1 point and an incorrect or don't know answer was assigned 0 points. Points are summed, divided by the total number of questions and multiplied by 100 to produce a percentage correct fertility knowledge score with a range of 0% to 100%. The scale was developed to examine fertility knowledge of male and female fertility. The questions were adapted to focus only on women's knowledge of female fertility. Participants received the demographic form and fertility knowledge instrument by email prior to interviews. Participants received an email with a link to a Qualtrics survey that included the demographic form and fertility knowledge questions.

Once demographic form and fertility knowledge questions were completed, interviews were conducted by phone. In-depth, semi-structured interviews were conducted between each participant and the PI. The PI developed an interview guide that contained open-ended questions with a series of pre-established probe questions to ensure

all participants were asked the same questions. Interview guide was approved by UAB's IRB. Interviews were audio-recorded, and PI remained in a private room throughout each interview. Interviews were transcribed verbatim and took approximately 45-60 minutes to complete. All data were stored on an encrypted and password-protected to maintain data confidentiality.

Trustworthiness of the Data

As with quantitative studies in terms of validity and reliability, it is important to establish rigor and credibility in qualitative studies. Strategies used to assess rigor in qualitative research address these standards: objectivity, dependability, credibility, transferability (Colorafi & Evans, 2016). Objectivity (confirmability) is described as the researcher's ability to be neutral and free of bias. This was addressed by providing a detailed description of the research method and addressing personal assumptions and potential prejudices (reflexivity and bracketing). Second, dependability (reliability) was supported by the uniformity of study processes among participants. This included the principal investigator conducted all interviews, following the same interview guide for each participant, and asking the same questions in the same order. The credibility of qualitative research provides a comprehensive "thick" description of the phenomenon of interest. This included spending sufficient time with participants to understand the culture and phenomenon of interest.

Data Analysis Plan

Information from the demographic form and the adapted Cardiff Fertility Knowledge scale were analyzed using R statistical software. Descriptive statistics of the demographic data were calculated for all participants, to provide a rich description of the participants. Thematic analysis is a commonly used technique to analyze qualitative research (Colorafi & Evans, 2016). Thematic analysis is when the researcher identifies, analyzes, and reports themes within data that will provide a detailed account of the data with common threads across multiple interviews (Vaismoradi et al., 2013). Thematic analysis includes familiarizing the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Colorafi & Evans, 2016). In the first step, the researcher repeatedly read the transcripts to familiarize herself with the data. The second step involved producing initial codes of the data. NVivo 12 (qualitative analysis computer software) was used to systematically organize the data. At the end of this step, data that was identified by the same code was classified together. The third step included searching for themes. In this stage, the focus is on the broader level of themes and involved sorting the different codes into potential themes (Colorafi & Evans, 2016). The fourth step included reviewing themes, which meant refining the themes. This included integrating some themes into others creating sub-themes. The fifth step included defining and naming themes, which involved ensuring that the themes captured the essence of the data they described. The final step was producing the report, which resulted in the final analysis and written report. Throughout the analysis, data were continuously compared with the findings of the current literature relative to infertility

help-seeking. The principal investigator (PI) consulted with the dissertation committee chair to receive feedback and discuss the final interpretation of the data.

Chapter Summary

This chapter provided in detail the methods that were used to conduct the study exploring infertility help-seeking among African American women. This included the design, sampling strategies, informed consent process, data collection plan, reliability and validity strategies, and the data analysis plan. A qualitative descriptive design was used to produce responses that described infertility help-seeking from the perspective of a sample of 12 African American women. Participants were recruited using various recruitment strategies (social media platforms, posting research flyers, etc.) through criterion and snowball sampling. Semi-structured interviews were used to collect data and strategies were in place to ensure rigor and credibility. Thematic analysis was used to categorize participants' responses into codes, themes, and subthemes to understand their infertility help-seeking. The next chapter will report the results and findings of the study.

CHAPTER 4

FINDINGS

This chapter reports on the findings of this qualitative, descriptive study. The chapter begins with an overview of the sample characteristics, followed by the descriptive statistics of the Fertility Knowledge Scale. Lastly, the qualitative findings from the semi-structured interviews are reported.

Sample Characteristics

In this dissertation study, there were a total of 12 participants from across the Southeastern United States. The age of participants ranged between 27 and 44 years (mean = 36.83, standard deviation = 5.41). The majority of participants were married (n = 18), held a university degree (n = 10), were employed full-time (n = 9), had private insurance (n = 11), and annual income between $50,000 to more than $100,000 (n = 10). Nearly half of the participants' religious affiliation was Baptist (n = 5). The total number of years with having difficulty getting pregnant ranged between 1.5 and 16 years (mean = 7.71, standard deviation = 5.33). See Table 1 for participant demographics.

Table 1

Participant Demographics

Demographics	Mean ± SD or (%)
Age	36.83 ± 5.41
Difficulty in Years	7.71 ± 5.33
Fertility Knowledge Scale	63.33 ± 20.6
Education	
Some College	2 (16.7%)
College Graduate	10 (83.3%)
Employment	
Full-Time	9(75%)
Self-Employed	3(25%)
Relationship Status	
Single	3(25%)
Partnered/Committed	1(8%)
Married	8(66.7%)
Insurance	
Government Issued	1(8%)
Private	11(91.7%)
Annual Income	
Less than $50,000	2(16.7%)
$50,000 -$100,000	5(41.7%)
More than $100,000	5(41.7%)
Religious Affiliation	
Baptist	5(41.7%)
Pentecostal/Holiness	1(8%)
Non-denominational	4(33.3%)
Seven Day Adventist	1(8%)
No Affiliation	1(8%)

The data for this study were collected via individual interviews. All the interviews were conducted by the Principal Investigator (PI). All 12 interviews were conducted via telephone using a semi-structed interview guide. Opening script and interview questions were preapproved by IRB. The participants were asked to describe their perspectives regarding the factors that hindered or aided their decision to seek assistance for infertility.

The interviews were audio recorded and took place at an arranged time and place convenient for the participants. Each interview time spanned between 45-60 minutes. Prior to each interview, the participants were provided with an information sheet that explained the purpose of the study, described study procedures, and presented them with the choice to participate or decline involvement in the study. The interviews were held in a private room with door closed to ensure maximum participant privacy. All data were stored on an encrypted computer to maintain the confidentiality of the data.

The data analysis process included listening to recorded interviews, reviewing interview transcripts, coding the data, developing themes from the coded data, re-listening to recordings and re-reading transcripts, developing and refining themes. To strengthen the trustworthiness of this study, a reflexive journal was created to account for researcher bias and prolonged engagement to reinforce accuracy and credibility of interpretations and findings.

Emerging Themes

Participants provided their perspectives on the factors that impacted their decision to seek help for infertility. Drawing from the collected data, three themes emerged: (a) barriers to infertility help-seeking, (b) facilitators to infertility help-seeking, and (c) recommendations to improve infertility help-seeking. Within each theme, there were several subthemes that will be presented in this section.

Barriers to Infertility Help-Seeking

Participants recounted various circumstances that acted as barriers in their decision to seek assistance for infertility. The barriers stemmed from different sources, including internal obstacles rooted in their personal beliefs and external hurdles originating from their social circle and the healthcare system. Though some responses varied among the 12 participants, the most common sub-themes that developed were knowledge and awareness, religious beliefs, challenging experiences with fertility specialists, perception of treatments, and infertility stigma.

Knowledge and Awareness

Cardiff Fertility Knowledge Scale. Participants described lack of fertility knowledge and awareness were barriers to infertility help-seeking. Prior to the interview, each participant was asked to complete a modified version of the Cardiff Fertility Knowledge Scale (CFKS) to assess fertility knowledge. Participant's individual scores ranged between 30%-100%. The questions that received the highest rate of correct answers focused on the impact of age on fertility (83%), the risks to fertility posed by smoking (92%) and sexually transmitted diseases (75%), as well as the accurate definition of infertility (92%). The questions that had the lowest correct response rate involved assessing whether fertility remains unchanged after age 40 (25%) and understanding the risks to fertility associated with being overweight (42%). The average overall CFKS score was 63%, (SD = 20.6). According to the developers of the scale, this is considered a modest score relative to the maximum score possible of 100% (Bunting et

al., 2013). Individual interviews with each participant were then conducted to further explore the factors that they perceived impacted seeking help for infertility.

During the interviews, participants were asked to discuss all the factors they were aware of that may affect fertility. Most participants suggested that certain lifestyle factors (smoking, diet, weight), hormonal imbalances (thyroid issues, polycystic ovarian syndrome), and age may negatively affect fertility. Regarding weight, only five participants correctly marked on the CFKS that being overweight by more than 28 pounds could affect a woman getting pregnant unassisted. Majority of the participants were unaware of the impact of weight on fertility until discussing treatment plans with fertility specialists. Participants mentioned that when seeking assistance for infertility, they were labeled as overweight and instructed to lose weight before proceeding with fertility treatments. Participant 5 stated:

> By their standards, my BMI is too high. So, they will probably tell me to lose some weight. It's something else. It's not my weight. But I mean, I'm not saying it's not a contributing factor and I know everybody's different, but you can't say that because I'm like 25, 30 pounds overweight. You want me to believe that a woman that's 450 pounds got pregnant, but my little 20 pounds is too much.

During the interviews, many of the participants expressed that their weight delayed their ability to receive fertility treatments. Participant 1 stated, “They're [physician] like, oh, just lose 20 pounds and we can consider you for treatment.” Participant 3 shared a similar experience, “They tell you, you got to lose weight, or they won’t move forward.” The frustration felt by many of the women was expressed by participant 12, “I have to lose weight and that's something I want to do, but it's extra

stressful now." Some participants agreed that it was discouraging that their weight was hindering them from receiving treatment. In some cases, participants had not initiated treatment past their consultation visit because they had not been able to lose the recommended weight.

Unaware of Treatment Options. All participants agreed that the knowledge and awareness of treatment options was a major barrier to seeking help for infertility. Prior to their fertility specialist consultations, several participants lacked information regarding infertility and treatment options. Participant 6 mentioned that there is a lack of awareness surrounding infertility and when to seek help. She also expressed uncertainty of whether it is "known widely" that infertility is defined as the inability to conceive after 12 months of trying.

Some participants did not realize that treatment options could include fertility medication, surgical procedures, and assisted conception (intrauterine insemination and in vitro fertilization). Participant 10 stated, "I had no knowledge when I went [went to see the doctor], I had no information prior to going." Most participants believed that women are primarily exposed to information about in vitro fertilization (IVF) and its high cost, while not realizing that medication alone may be sufficient for their needs. Participant 7 explained that the notion of fertility assistance often invokes the perception of requiring "thousands of dollars upfront," when it may not necessitate such extensive measures. "Sometimes you just might need ovulation stimulation with something like Clo [Clomid]" (Participant 7). Participant 12 reiterated that some women may only need

medications or diet modifications, but they don't seek help because "they don't know about the options." Participant 12 stated:

> I wonder if people sometimes don't go do it because oh only the worst people having the worst time go. And so, people aren't really aware that you don't have to wait till it's bad to go seek help or least have those conversations.

Cultural Norms and Beliefs. Participants primarily attributed their lack of knowledge and awareness to cultural norms and beliefs. African American cultural norms often constrained fertility knowledge and awareness among many participants, creating a barrier to help-seeking. According to the participants, infertility remains a taboo subject within the African American population, often left unaddressed and unspoken. Participant 6 stated, "I feel like it's something that's still taboo and it probably is related to people not understanding the process or actually the science behind what actually happens." Participant 12 reiterated, "I'm from an environment where you don't really try after you try, and you fail. You know, you don't go and try to get medications or get help or assistance." Participants further emphasized that privacy is highly valued within the African American culture, especially regarding sensitive matters. Participant 6 stated, "Growing up, it was really never discussed if they (family members) had issues getting pregnant." Participant 10 added:

> I think that goes back to us learning or being taught what goes on in the house stays in the house. Don't be telling your business, don't talk about your business with nobody and things like that. So, you don't even talk about it or anything at all.

Participant 11 inferred that because being private and not discussing things "outside the home" is so important in the African American culture, "It kind of holds us back and stops us from getting the information and the help that we need." Participants suggested that due to the lack of open discussions about infertility, women may be led to believe that African American women do not experience fertility issues. The participants collectively agreed that there exists a stereotype suggesting that African American women are not prone to fertility issues. Participant 6 stated, "Everybody else is getting pregnant, so why would it be a problem for me? I shouldn't have any problems." She continued:

> It kind of let me know that that was an assumption and that was not a fact because women from all races can go through it. Infertility is not something that black women are excluded from.

Participant 7 added, "It's no way that I would have an issue because I've never heard any of my family members dealing with anything like that." Participant 12 expressed, "Black women just can handle it all and don't really have problems when it comes to reproductive health." The prevailing belief among participants is that this stereotype causes delays in recognizing and addressing potential fertility issues among African American women.

Religion and Spirituality. Participants' religious and spiritual beliefs emerged as a barrier to infertility help-seeking. For many, their religious beliefs led to delays in seeking assistance, as they felt compelled to rely solely on faith rather than pursuing medical treatment. Participants associated this barrier with cultural aspects, noting that

within the African American community, there is a significant reliance on spirituality when confronting health-related challenges. The perception of relying on prayer and the belief that God would intervene rather than actively seeking help was commonly reported by participants. Participant 2 reported it took her “so long” to seek help because she wanted to “just pray about it and leave it to God.” Participant 11 added that her religious beliefs led her to “wait a bit longer” to seek help than what was recommended by medical standards. Participants perceived that seeking help would interfere with “God’s plan.” Participant 7 stated, “You're not letting God work or you're not letting God do it.” She elaborated, “If you get assistance, then it is more so well you putting your hand in God's way.” Participants expressed their hesitancy in sharing their struggles with infertility within their religious or spiritual circles. The primary concern stemmed from the fear of receiving negative comments that could potentially influence their decision about seeking help. They preferred to safeguard their own judgment and not be swayed by others' opinions in this sensitive matter. Participants described hearing comments stating that having kids may not be “God’s will” or “not His timing” refrained them from discussing their own person struggles. Participant 3 noted a comment she had heard made to others, “If you can't have any, I mean God didn't want you to have it.” Participant 7 stated she did not tell people because she knew they would encourage her to “pray about it and fast.” She stated, “If I would’ve told them and they would've hit me with my faith isn't strong enough, it would've turned me away from them. And I knew that.” She noted that would have caused her more stress and anxiety in an “already stressful situation.”

For some participants, their religious and spiritual beliefs emerged as both facilitators and barriers to infertility help-seeking. Participant 6 stated:

> There was some internal conflict because sometimes I feel like there are times when we want something to happen, but that might not be in God's timing. Well, if it's not the time for this to happen, then even if we go through this process then it won't work. Even though we can pray about things, there are things that can also help us along the way. And it's not to be shameful if sometimes we have to use other resources as well.

Participant 2 stated, “God will do it in his way, but sometimes you have to go out and seek help.” Participant 3 reflected on her experience, firmly expressing her belief that God gave doctors the ability to provide assistance, and it should be utilized. She further explained that she felt God played a role in her ability to try IVF because she believed He “knew that’s what I really wanted, and He made it happen.” Participant 11 expressed her belief was “to do everything I can and let God do the rest.” She also highlighted how her spirituality played a crucial role in coping with the inability to conceive and provided significant emotional support throughout the process of seeking help.

Challenging Encounters with Fertility Specialists

Participants in the study revealed that their interactions with fertility specialists posed significant barriers to seeking infertility help. Many expressed feeling unheard and neglected during these encounters, with their questions and concerns often left unanswered. Participant 1 reflected, “I think when you have doctors that don't seem like they care, that you're just another number, I think that deters,” from seeking help. Discussing their difficulties in conceiving with physicians proved challenging,

particularly as some felt that certain aspects, such as cultural struggles and misconceptions, were not fully understood by the specialists.

Participants revealed concerns about potential cultural misconceptions surrounding African American women and their engagement in infertility help-seeking. Participants believed that certain specialists might hold the misconception that they could not afford treatments, which may have negatively impacted their care. Participant 10 reflected on her experience when a particular supplement was not offered to her but was offered to another patient that was a White woman:

> I asked the doctor, I was like, I heard this lady talk about these different vitamins. And so she was like, yeah, she said they're kind of expensive, but we do have patients who do take these vitamins. So I don't know if the doctor thought maybe I couldn't afford it. So that could lead into the stereotype of them thinking we don't have the money.

This misperception added an additional layer of frustration and difficulty to her journey towards seeking infertility assistance and prompted her to consider the possibility of bias in the availability of treatments offered to African American women.

Additionally, the thought of possibly not being able to get pregnant was emotionally taxing, and one participant pointed out that most fertility specialists being male might hinder their understanding of the profound implications of such a diagnosis for a woman. She stated, “This is a male driven profession. Men will never, ever in their life understand the experience of being told you can't have kids without assistance for a woman regardless of the race.”

Several participants shared that their pursuit of further treatment was delayed following consultations with specialists. Participant 6 acknowledged, “If a provider does not have your best interests at heart or is not willing to work with you through the process, then I think that's another deterrent from seeking help for fertility.” For some, this delay resulted in either not returning for additional treatment or significantly prolonging the time before they resumed treatment. Participant 1 shared her experience stating, “Yes, my doctor did delay me, from seeking help because, he told me that I shouldn't worry about it.”

Weight Matters. Numerous participants expressed that they faced difficulties with receiving help because of their weight and high BMIs. Participants reported feeling discouraged because they believe that higher BMIs disproportionately affect African American women and that physicians failed to acknowledge this reality. According to participants, instead of specialists considering the cultural dynamics surrounding weight, they often offered a generic recommendation to lose weight without understanding the unique challenges faced by African American women in this regard. Participant 12 expressed that because African American women tend to fall in the category of being overweight, and not meeting fertility treatment BMI standards, it prevents African American women from pursuing treatment. She further explained:

> I think that may be another way Black women are not getting the care they need because before they get sent to fertility specialists, OBGYNs, or general care providers, will tell them they need to go ahead and lose the weight because they're going to tell you to lose anyway.

Participants reported that the requirement to lose weight before even considering treatment amplified the stress of their infertility help-seeking journey, with a few of them refraining from seeking further assistance. Participant 3 explained, “I kept trying [to lose weight] and then I kind of gave up.”

Perception of Treatments

Participants’ perceptions of infertility treatments were identified as a major barrier to infertility help-seeking. Participants reported they delayed seeking help for infertility because of the perceived costs of fertility treatments such as in vitro fertilization and intrauterine insemination. Fertility treatment options were reported as expensive, and many participants stated that cost of some treatments made treatment “out of reach.” Participant 1 stated, “You kind of worry about the cost, so we didn’t think about it because it was expensive.” Participant 3 added, “I never really thought about the whole IVF stuff because one, I thought it cost too much and I didn't have the money for that.” She continued, “I was reluctant of the IVF cause I knew IVF costs a lot of money and a lot of people, they always say, oh no, IVF is for the rich people.” Participants who opted for fertility treatment alternatives, aside from IVF, mentioned it would have been a delay in seeking help because of the cost of IVF. Participant 6 stated, “If we had to progress to doing IVF, I do know that that would have been something that would not have happened in that quick timeframe we did with the IUI.” Participant 10 stated that she would “need to get my funds back up” to try IVF because it is a “very expensive process.”

Facing the Costs Alone. Many participants reported that cost was a major barrier because the medications and procedures are not covered by insurance. Out of pocket costs for treatments attributed to most of the participants' apprehension towards seeking treatment. Participant 3 expressed that because insurance didn't cover IVF, she knew that she "couldn't go that route," and that she may be able to try medications at some point. Although some testing may be covered by insurance, participants stated the process of seeking help was still expensive. Participant 10 added, "Maybe some labs have been covered, but as far as anything else, we had to come up out of our pocket with something."

Discouraging Fertility Treatment Outcomes. The lack of success in fertility treatments was identified as a barrier to continuing seeking infertility assistance. Participants elaborated on how the fear associated with the process and the prevalence of unsuccessful outcomes acted as barriers to seeking help. Participant 9 explained, "Sometimes you just don't want to know," which creates a level of fear regarding the process of seeking help. Participants expressed that seeking help and finding out something is wrong is something that may be too hard to bear. As Participant 12 put it, "At some point you just get tired of the waiting and the tired of the emotions surrounding the experience." Participants expressed significant concern about undergoing treatments and grappling with the emotions in case of unsuccessful outcomes. Participant 9 added, "The fact that you can have the money, pay the money for IVF, and it may or may not work. I feel like the risk factor is too high." She further expressed her discouragement, stating that she would be more inclined to consider IVF if the success rates were higher.

Infertility Stigma

Participants all agreed that stigma was a barrier to infertility help-seeking. Participants described feeling embarrassed or shame after realizing they were not able to get pregnant. Participant 2 reported feeling embarrassed and depressed due to her inability to have a child. For Participant 11, using the word 'infertility' made her feel embarrassed and reluctant to discuss it. She added, “We don’t really want to talk about [infertility]” because it is abnormal. Participants agreed that having children is a societal norm, and not being able to do so appears abnormal, which consequently leads to negative thoughts and feelings. According to Participant 3, there is a stigma surrounding infertility and it can be perceived as people thinking, “What’s wrong with her?” Participants expressed that the stigma surrounding infertility prevents them from openly discussing their struggles and seeking help, as they fear encountering negative thoughts and comments associated with it. Participant 6 stated, “I just felt like I just didn't want to hear the questions or the negative comments about it.” Participant 6 also expressed that when you are unable to have your own child, "it feels like it separates you" from your family. Participant 7 stated that women don’t want to seek help because of the “negative viewpoint.”

Participants also reported experiencing internal stigma, in addition to the external stigma from others. Participant 2 explained that despite her husband being supportive of her seeking help, she felt he looked at her differently because she could not have a child. This negative self-perception persisted even though she did not experience stigma externally. Participant 9 explained, “I feel like we view ourselves negatively. I personally

feel like something's wrong with me, but I don't necessarily feel like people think something's wrong with me."

Facilitators to Infertility Help-Seeking

Participants were asked about the factors that facilitated their pursuit of assistance for infertility. A variety of responses emerged, shedding light on the factors that empowered them to seek help. The subsequent sub-themes highlighted the significance of a strong support system and cultivating resilience in the face of infertility challenges.

Supportive Family and Friends

Participants considered the support of their family and friends as a major facilitator for infertility help-seeking. A positive support system helped ease the challenges and stress of dealing with infertility and the process of seeking help. Participant 1 stated she had family members, including her spouse, that "were always there," and they were very supportive. Other participants also experienced a sense of support from their family while seeking assistance for infertility. Participant 3 shared, "My husband was very supportive. He was supportive with whatever I wanted to do." Participant 11 also shared an experience about her mother's emotional and financial support in seeking help, which resonated with her due to the high costs of fertility treatments. She shared, "When I told her, her immediate response was like, okay, we'll make it happen. So that was a touching moment for me to hear my mom say that because it's expensive."

Participant 2 and Participant 7 also expressed how having encouraging friends facilitated seeking help. Participant 2 shared, “They're helping, they have been on Google searching different things, coming and talking to me about what they might have found.” Participant 7 said, “My best friend really pushed me to go and have a conversation with my doctor.” Participant 8 shared how having a strong support system is necessary when seeking help for infertility. Participant 8 stated:

> You really need a strong support system because everyone doesn't understand. There are some people that I'm close to, they still don't understand the process. I tried to explain it to them, but they don't understand it. But it's so much because it is a mental journey and it could be draining, mental, physical, spiritual, emotional, all of that. So you really need a super, super strong support system. And I feel like if the spouse or the partner isn't on board, it's not going to work.

Participant 11 stated, “I think if someone had a family or a partner that didn't believe in IVF think that would deter anybody.” Participants agreed that having an unsupportive partner or family would make seeking help more stressful and would make it difficult to go through the process.

Fostering Resilience

Participants agreed that cultivating resilience played a pivotal role in driving their pursuit of infertility help-seeking. They described having a mindset of perseverance, remaining undeterred by obstacles as they sought help. This determination was often characterized as a willingness to do “whatever they can do” to try to conceive a child. Participant 5 stated, “I still wanted to try just to say that I did everything that I could do.”

Participant 1 explained that having a child is something that she wants and stated that other's opinion about the decision was not a major barrier. Participant 1 stated, "This is what I wanna do. I don't feel like I need anyone's input." Participant 2 explained, "With my husband, whether you on board or not, this is what I want to do, and this is what I'm going to do." Participants attributed their resilience and the motivation to seek help to the overwhelming importance of motherhood. Despite encountering barriers like negative interactions with physicians and dealing with societal stigma, their unwavering desire to embrace motherhood persisted. Participant 6 described motherhood as being important because it would allow her to share unconditional love and have a legacy. Participant 9 shared, "Since I truly do desire to be a mom, I feel like I just don't have any reservations about asking somebody what they know or how they can help."

Recommendations to Improve Infertility Help-Seeking

Throughout the interviews, participants voiced their insights on ways to improve infertility help-seeking. When questioned about their recommendations for enhancing infertility help-seeking within their demographic, participants revealed three main sub-themes: increase awareness and understanding of infertility and its treatments specific to African American women, improve infertility care to ensure consistent provision of care and resources across all fertility clinics, and a desire for greater openness among African American women in sharing their infertility experiences and seeking assistance.

Increase Awareness and Knowledge

Participants agreed that there should be more information about infertility and treatment options. Participants shared that in most instances, they did not know how common infertility was until having their own personal struggle. More awareness specifically targeting African American women was described as a potential way to improve infertility help-seeking among African American women. Many participants described providing educational resources on infertility and treatment options. Participant 1 shared, "Maybe having some educational resources, that may would also help in making the decision to seek help." Participant 2 said, "Educate, educate, I wish there was more education out there." Participants suggested that education should be provided on infertility and not just when a woman realizes she is having an issue. Participants indicated that it would be beneficial if obstetricians/gynecologists could offer more information about fertility, as many of them lacked comprehensive knowledge before encountering difficulties. Participant 12 described spreading fertility knowledge and awareness to younger age groups to address preventable risk factors for infertility and offer insights into available options if prevention is not feasible.

In addition to increasing awareness about infertility, participants also suggested providing information about the treatment options would also be helpful in infertility help-seeking. They mentioned that they were unaware of less invasive alternatives, only being familiar with IUI and IVF. Participant 12 shared, "Some people just have to do medications and other things that are less invasive, and they don't know about the options. To have the information about that option would be helpful when making the decision to seek help." Additionally, many were unaware that certain infertility issues

could be addressed through ovulation monitoring or ovulation induction using medication. The lack of awareness about these options led participants to postpone seeking assistance, despite eventually achieving success with less invasive measures.

Improve the Infertility Help-Seeking Experience

Participants reached a consensus on the critical importance of infusing fertility care with compassion and essential resources to effectively address the challenges of infertility. A recurring theme among participants was a notable dissatisfaction with the level of empathy displayed by fertility specialists, often leading to feelings of neglect. It was strongly advised that physicians and their support staff enhance their approach by cultivating a deeper sense of compassion, recognizing that the infertility help-seeking journey is burdened with stress and emotional turmoil. In emphasizing the significance of this aspect, participant 1 stated, “Find someone who will listen so that you won't feel like you're not being listened to.” Participant 8 added, “We need physicians in place who are actually going to listen and take the patient's desires into consideration. We need to be heard and be seen and to know that it's okay that we’re, not alone.”

Several participants proposed the inclusion of a dedicated nurse, counselor, or patient advocate to guide individuals through the complexities of seeking fertility help. Participant 3 shared, “We need somebody there that knows the process of the whole IVF or just the road that you'll be taking where they can help walk you through it.” Furthermore, a call for consistency emerged, suggesting that fertility clinics universally offer information on key resources, such as financial assistance options (grants, loans, etc.) or specialized support, tailored especially for minority patients. Recognizing

treatment costs as a major barrier to accessing infertility care, participants strongly advocate for the establishment of more affordable treatment alternatives and the inclusion of treatment coverage within insurance plans. Participant 9 expressed, “I would like to see some other options [other than IVF] that are more cost effective or something just that has been more successful in helping people.” Participant 11 added, “Cause if they [fertility treatments] were more affordable you would do it more.” Participants also suggested more inclusion of minority populations in infertility research to bring more awareness. Participant 11 stated:

> A lot of the results like the fertility treatment outcomes for Black women are not that great, but when it comes to doing the research part of it, we not included a lot. I mean they're creating treatments that would be effective for the people that they are doing the research on.

Encourage Black Women to Share Their Infertility Help-Seeking Journey

Participants discussed how it would have been helpful to have known other women that had sought help for infertility prior to their journey. They expressed they felt like their experience was an isolated event because they did not know of anyone who had sought help for infertility. Participant 1 suggested that African American women should discuss infertility help-seeking to raise awareness about the issue. Participant 5 pointed out that even though a partner or spouse might be supportive, they may not fully comprehend the emotional difficulties. She shared, “Having a woman to talk to about women things is paramount to your sanity.” She shared her observations about friends who experienced a sense of isolation and “feeling cut off” during their own infertility

journeys. She added, “I was kind of sad that they didn't have me as a resource when they were going through it.” Participant 6 explained that “maybe hearing about someone’s experience who looks like you, makes it more meaningful.” Participants recognized that it may be difficult for women to share their experiences, but they agreed that knowing they were not alone provided significant emotional support. Participant 12 shared, “I think it's important to see other people who look like you that have been through the journey.”

Participants also recommend having support groups specifically catered to African American women. They acknowledge that certain support groups exist on social media platforms, but many of them state that these groups do not offer the emotional support they require or are not tailored specifically to African American women. Participant 12 recommended fertility clinics would be a great place to help connect women of color to develop support groups. Some participants mentioned that the fertility clinics they utilized provided support groups, although this service was not available at all clinics.

Chapter Summary

This chapter reported on the findings of this qualitative descriptive dissertation study. The chapter provided an overview of the participant characteristics followed by the findings of the participant interviews. The findings revealed that the lack of fertility knowledge and awareness, negative experiences with fertility specialists, perceptions of treatments, religious beliefs, and infertility stigma were major barriers to infertility help-seeking. Findings also revealed that a strong support system, and fostering resilience in

the face of infertility challenges were major facilitators for infertility help-seeking. A myriad of recommendations for infertility help-seeking were offered, including increasing fertility awareness and knowledge, improve infertility care and resources, and encouraging African American women to share their infertility help-seeking experiences. Chapter 5 will provide an overview of the research questions and reported findings and explore their implications for nursing practice.

CHAPTER 5

DISCUSSION

The purpose of this qualitative descriptive study was to explore the factors that influence African American women to seek help for infertility. The women in the study agreed that their fertility knowledge and awareness were barriers to seeking help for infertility. Some of the women were able to identify some risk factors for infertility (smoking, alcohol, STDs, etc.) but did not have much understanding how age and weight affect fertility. These findings are consistent with the current literature showing that women of childbearing age, specifically African American women have limited fertility knowledge on how age and obesity affect infertility (Dodgen & Spence-Almaguer, 2017; Wiltshire et al., 2019). Approximately 42% of women in this study correctly associated increased difficulty with fertility and being overweight by > 28 lbs. However, many of the women were not aware of the effects of weight and age on fertility until going to fertility specialists for consultations. There were a few women that continued believing weight did not affect their fertility. This is of clear concern as obesity is a modifiable risk factor and African American women have a 57 % higher prevalence of obesity compared to other racial groups (Lofton et al., 2023). Research is necessary to investigate the extent of fertility health education provided to African American women by primary care providers and obstetrician/gynecologists, given the currently low levels of fertility knowledge.

As delayed childbearing becomes increasingly common in our society, patient awareness of the impact of age on fertility is growing in significance. Only 33% of the women knew that the likelihood of conceiving is different between a woman aged 30 vs. 40 years. This is consistent with Wiltshire et al.'s study (2019), showing that African American women were significantly less aware of the impact age has on infertility.

Lack of awareness of infertility treatment options was identified as a barrier to seeking help. Most of the women were only familiar with assisted reproductive treatments (ARTs), such as in vitro fertilization (IVF) and intrauterine insemination (IUI) but were not familiar with noninvasive treatments such as ovulation tracking and medication. The existing literature states that women of childbearing age lack significant knowledge of treatment options (Hoffman et al., 2020). While consistent with existing literature, this study's findings offer a distinct contribution by addressing a notable gap—previous studies on knowledge of treatment options rarely included adequate representation of African American women. The women in this study agreed that if they had known about the noninvasive options, they would have sought treatment sooner. The findings of this study provide valuable insights into the influence of knowledge about treatment options on treatment seeking for African American women.

Challenging encounters with fertility specialists was the most significant barrier to seeking help for infertility. This finding is congruent with the existing literature expressing that the patient-doctor relationship has been identified as an important factor in women seeking fertility treatments and sustaining treatment plans (Dancet et al., 2012; Domar et al., 2021; Klitzman, 2018). The women in this study felt that their providers overlooked their concerns and noted their insensitivity and disconnection. This study

enhances the literature by offering a unique perspective on how African American women perceive themselves to be viewed by their providers and how that perception impacts treatment seeking. As noted by some women from the study, the patient-provider disconnect may stem from the predominantly male nature of the profession, potentially overlooking the challenges faced by women in not becoming mothers and the potential influence of racial bias. Previous studies suggest that despite income and insurance coverage, persistent disparate outcomes for African American women may also be explained by provider bias and gatekeeping (Ghidei et al., 2022). This sentiment was conveyed through women's reports of unequal treatment information delivery, with some feeling that certain information was offered to White women but not to them, and clinic staff making assumptions about their ability to afford treatment. While consistent with existing literature that documents the experiences of racial bias among African American individuals seeking treatment for health conditions, this study stands as one of the first to report potential bias in the context of seeking infertility assistance. Future research is warranted to deepen our understanding of provider characteristics and the patient-provider relationship in the context of infertility help-seeking for African American women.

In regard to African American women's beliefs about infertility and fertility treatments, there were common cultural misconceptions that the women identified. In this study, the women expressed their lack of awareness regarding infertility as a common issue among African American women, only becoming aware of it when seeking treatment, often attributing this to the misconception that fertility issues are rare among African American women or the discouragement of discussions about infertility within

their community. This is of critical concern as this misconception leads African American women to overlook potential fertility issues and delay seeking treatment. More research is needed to explore the impact of cultural misconceptions on infertility help-seeking among African American women.

Through the conversations in the individual interviews, it was apparent that the women's spiritual beliefs were a barrier to infertility help-seeking. Delay in help-seeking was attributed to spiritual beliefs, and the women in this study indicated that they would have sought help earlier if these beliefs had not been a factor. This result can be ascribed to the importance of spirituality and its impact on treatment seeking behavior in the African American culture (Dessio et al., 2004). This was not identified in the current literature; thus, it is an important contribution to the literature in that it begins to shed light on the importance of spirituality to infertility seeking for African American women. Some of the women in the study reported that their spiritual beliefs helped in coping with infertility, which has been described in the literature (Honarvar & Taghavi, 2020). Spiritual beliefs might have varying effects on infertility help-seeking, depending on one's religious affiliation. Further research is needed to explore religious affiliations of African American women dealing with infertility and how it relates to infertility help-seeking.

The most frequent concern regarding fertility treatments was cost and not covered by insurance. The current literature describes that perceived cost is consistently identified as a major barrier to fertility treatments across all racial groups and contributes to the disparity in fertility service utilization among minority population, specifically African American women (Domar et al., 2021). Although there have been strides made, there is a

continued need to advocate for policy change as it relates to insurance coverage for infertility care. This study emphasizes that while cost is a contributing factor to help-seeking, it was not identified as the main barrier, suggesting the presence of other significant factors influencing this decision. More research evaluating infertility service utilization in states with mandated insurance coverage is needed to understand the barriers that persist when African American women are deciding to seek help for infertility.

The perception of the women in this study revealed that unfavorable fertility treatment outcomes were a concern while deciding to seek help for infertility. Low success rates created apprehension for African American women to seek help. This aligns with existing literature, which has previously pointed out the underrepresentation of African American women in infertility research, and among those who do participate, they experience disproportionately lower rates of live births after ART compared to White women (Chin et al., 2015; Jain, 2020; Wiltshire et al., 2019). The findings of this study add to the literature by highlighting the significance of ART success rates in influencing the decision of African American women to seek assistance for infertility. Continued research is needed in exploring ART outcome rates among African American women and further understanding of the causes of failure.

The presence of stigma was a significant challenge when seeking help for infertility. The women in this study agreed that stigma played a major role in delaying or not seeking help for infertility which is consistent with the current research stating infertility stigma is a barrier to seeking help (Blevins et al., 2013). For African American women, the severity of infertility stigma is significant and often leaves them to “suffer in

silence" (Ceballo et al., 2015). The findings of this study contribute to the literature by highlighting that, beyond external infertility stigma, the effects of internal stigma are even more significant for African American women. They expressed reluctance to seek help due to fear of external judgment and, more importantly, an internal sense that something was inherently wrong with themselves. Internal infertility stigma in African American women is understudied. Further research is needed in this area.

Having a strong support system was the most important factor in facilitating seeking help for infertility. This result is consistent with existing studies on the positive influence of family and friend support on infertility help-seeking. (Gibson and Myers, 2002; Martins et al., 2011). While the current literature (Lei et al, 2021; Malina et al., 2019) focuses mainly on the support of the partner and family, the findings of this study highlight the importance of the support of female friends. According to the women in this study, receiving support from others who have shared similar experiences significantly aided them in navigating the process of seeking help for infertility. Given the reluctance of African American women to openly discuss their infertility struggles, the women in this study emphasized the value of hearing others' journeys when seeking help, accentuating the importance of a strong support system in the context of seeking help for infertility. Therefore, further research is warranted to explore the social networks of African American women, with the aim of informing communication strategies that facilitate sensitive conversations regarding seeking help for infertility.

Resilience is a major characteristic that facilitates infertility help-seeking among African American women. The women in this study expressed their unwavering determination to overcome challenges, particularly driven by their deep desire to become

mothers, which served as a significant motivator for seeking infertility assistance. This aligns with the existing literature as the role of motherhood has been described as an enabler to help seeking for all women (Foti et al., 2023; Grei et al., 2019) The findings of this study bring to light the importance of motherhood for African American women, as previous studies lacked substantial representation of this specific population. When grappling with the emotional distress of infertility and mustering the courage to seek help, it becomes essential for women to cultivate a profound sense of empowerment to navigate the obstacles they may encounter. While resilience has been explored as a coping mechanism in the context of infertility, its significance in the help-seeking process has not received widespread attention. However, given its apparent importance to the women in this study, it raises the possibility that those who do not seek help may face challenges related to resilience. Notably, the African American women who met the study criteria but had not sought help for infertility, did not wish to participate in the study. Resilience can serve as a catalyst for open discussions about the sensitive subject of infertility and encourage individuals to seek assistance.

Implications

The findings of this study indicate the need for further research into the factors influencing infertility help-seeking, with potential implications for informing interventions and policies aimed at reducing disparities in infertility service utilization among African American women. This section elaborates on how this study can contribute to clinical practice, policy, and future research.

Practice

For practice, providers can address African American women's perception of gaps in communication and relationship with their providers. The data from this study highlight the significance of positive interactions between African American women and their healthcare providers, as the absence of such interactions could potentially impede their pursuit of treatment. Additionally, the findings of this study carry significant practice implications, emphasizing the necessity to enhance provider and staff training in effective and culturally sensitive communication to better meet the healthcare needs of African American women seeking infertility assistance.

It is widely acknowledged that infertility can lead to psychological distress, and it is recognized that patients can find relief from this distress through mental health support. Still, patients may struggle to connect with needed mental health support on their own. The findings from this study suggest that African American women can benefit from having a mental health provider (MHP) within the fertility care team. Research in other medical fields show that integrating MHPs into clinics provides the greatest benefit to patients and medical teams (Sax & Lawson, 2022). To effectively identify patients at risk of psychological distress and in need of psychological support, fertility clinics should embed these specialists into the fertility care team.

Policy

The results of this study also accentuate the ongoing necessity of mandating insurance coverage for fertility treatments, as it has been observed that enabling such coverage encourages women to seek assisted reproductive help at a younger age, which is

a critical factor contributing to the success of live births after IVF (Jungheim et al., 2017). The data from this study suggest that this could serve as a motivating factor for African American women to seek help earlier.

Research

Several factors play a role in women's decisions to seek help for infertility, and this study specifically sheds light on the determinants influencing African American women in this regard. As mentioned in the previous section, although efforts were made to include those who had not sought help for infertility in the study, this goal was not achieved. Hence, there is a clear need for further research to explore the factors contributing to the decision of some African American women to forego seeking help for infertility. Resilience was identified as a major enabler to seek help. Future research should investigate the role of resilience and its influence on the infertility help-seeking decision process.

The identified barriers to infertility help-seeking suggest avenues for future research aimed at promoting help-seeking behaviors among African American women. Fertility knowledge and awareness is widely studied but previous studies fail to have adequate representation of African American women participants (Hoffman et al., 2020; Wiltshire et al., 2019). This study highlights that fertility knowledge among African American women is minimal but impacts their decision to seek help or not. Further research is essential to investigate the fertility knowledge of African American women, with the aim of informing educational interventions that can enhance their understanding and enable them to make informed decisions about their fertility health.

The study's findings emphasized the significant impact of African American women's interactions with their fertility specialists on their help-seeking behaviors and treatment adherence. To gain a comprehensive understanding of the communication disconnect between patients and fertility specialists, incorporating both perspectives is essential, highlighting the need for ongoing research in this domain.

The cultural and spiritual beliefs of African American women were found to significantly influence their decision-making process when seeking help for infertility, providing valuable insights into an underrepresented area within fertility research. There is a clear need for further research to investigate how these cultural and spiritual beliefs shape decisions related to infertility help-seeking, and to explore ways in which healthcare providers can enhance their support in this regard.

In the context of infertility stigma, the findings of this study contribute novel insights by shedding light on internal infertility stigma, further enriching the existing literature. Additional research is warranted to develop strategies aimed at reducing internal infertility stigma, with the potential to enhance infertility help-seeking among African American women.

Fertility knowledge and awareness, cultural beliefs, fertility specialist interactions, spirituality, infertility stigma, social support, and resilience emerged as notable factors influencing infertility help-seeking. Additional research with larger sample sizes is warranted to delve deeper into these factors and explore strategies for mitigating these challenges and enhancing the positive factors. This effort can help bridge the gap in infertility help-seeking among African American women.

Strengths and Limitations

As with all research, this study is not without limitations. Recruitment strategies were implemented to maximize the inclusion of African American women who have not sought help for infertility. Regrettably, among those who expressed interest and met the criteria, none opted to participate in the study. Gaining insights from those who have not sought help may unveil different challenges in seeking assistance compared to those who have. Qualitative research and small sample size (12) limits findings to this specific sample and are not generalizable. To address this issue, efforts were made to ensure that the sample represented a range of socioeconomic backgrounds (education level, relationship status, annual income).

Qualitative research standards were adhered to regarding sampling, data collection, and analysis. Credibility and trustworthiness were ensured through prolonged engagement, reflexivity, and data saturation. Interview transcripts were reviewed and verified by participants and themes were also shared to ensure they are reflective of their experiences (Creswell & Plano Clark, 2018).

Conclusion

Seeking help for infertility is impacted by various factors. For African American women, the challenges they encounter differ in certain aspects, and this study provides a unique perspective on this substantial yet often underrepresented population of women by examining the factors influencing their infertility help-seeking behavior. The study findings revealed fertility knowledge and awareness, patient-doctor relationship, infertility stigma, religious and spiritual beliefs, perception of treatments, family, and

friend support, and fostering resilience were all factors that impacted infertility help-seeking. Recommendations were made by participants to improve infertility help-seeking among this population. The study findings can inform future research, policy, and practice to improve infertility service utilization for African American women.

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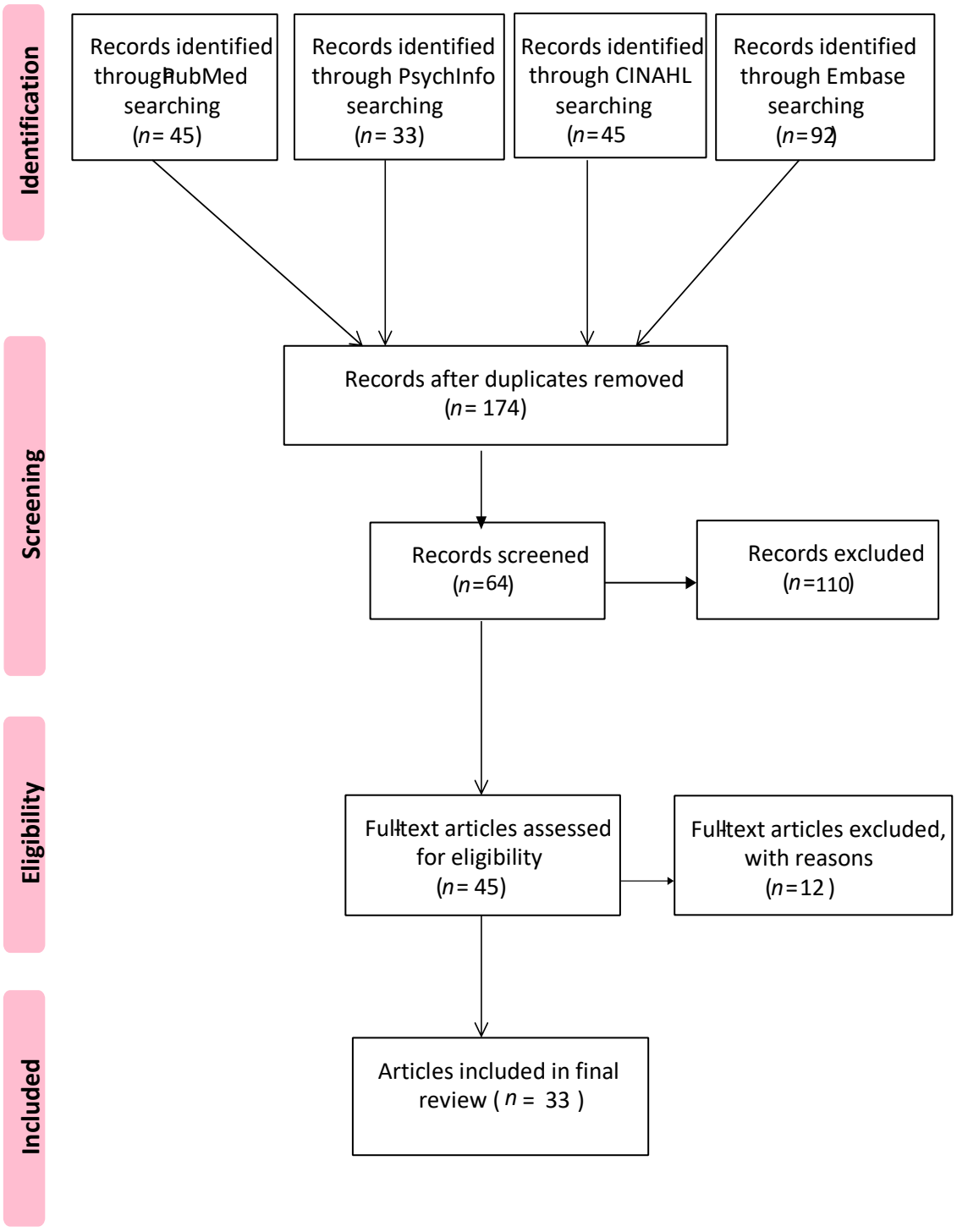
APPENDIX A

PRISMA DIAGRAM

PRISMA DIAGRAM



APPENDIX B

INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

470 Administration Building
701 20th Street South
Birmingham, AL 35294-0104
205.934.3789 | Fax 205.934.1301 |
irb@uab.edu

APPROVAL LETTER

TO: Wells, Andrea Gosa

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance # FWA00005960
IORG Registration # IRB00000196 (IRB 01)
IORG Registration # IRB00000726 (IRB 02)
IORG Registration # IRB00012550 (IRB 03)

DATE: 17-Aug-2022

RE: IRB-300003616
IRB-300003616-002
A Qualitative Descriptive Study Exploring Infertility Help-Seeking Among African American Women

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The IRB reviewed and approved the Initial Applica on submitted on 16-Aug-2022 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Exempt
Exempt Categories: 2
Determination: Exempt
Approval Date: 17-Aug-2022
Approval Period: No Continuing Review

Documents Included in Review:

- IRB EPORTFOLIO
- IRB PERSONNEL EFORM

To access stamped consent/assent forms (full and expedited protocols only) and/or other approved documents:

1. Open your protocol in IRAP.
2. On the Submissions page, open the submission corresponding to this approval le er. NOTE:

The Determination for the submission will be “Approved.”

3. In the list of documents, select and download the desired approved documents. The stamped consent/assent form(s) will be listed with a category of Consent/Assent Document (CF, AF, Info Sheet, Phone Script, etc.)

APPENDIX C

RESEARCH STUDY INFORMATION SHEET

INFORMATION SHEET TO BE PART OF A RESEARCH STUDY

Title of Research:	A Qualitative Descriptive Study Exploring Barriers to Infertility Help-Seeking Among African American Women
UAB IRB Protocol #:	IRB-300003616
Principal Investigator:	Andrea Wells, MSN, RN

PURPOSE OF THE RESEARCH

You are being asked to take part in a research study. The purpose of this research is to find out what keeps African American/Black women from seeking help to get pregnant when having difficulty. The objective is to talk with African American/Black women to find out from their point of view, what are some of the barriers they encounter when deciding to seek help to get pregnant. Recent research indicates that African African/Black women have more difficulty getting pregnant than Caucasian/White women but are less likely to seek help. As the principal investigator, I hope to learn more about why this happens so that healthcare providers can provide better services and support for African American/Black women in this situation.

EXPLANATION OF PRIVACY PROCEDURES

If you agree to participate in the study, an in-person, telephone call, or audio-visual interview (ZOOM) will be scheduled, and the time and date will be at your convenience. In person interviews will be audio recorded and only the two of us will be present in a private room. Before the interview, you will be asked to complete a brief fertility knowledge questionnaire as well as a demographic form. Your name or identifying information will not be included on the questionnaire or the demographic form. It is expected to take approximately 15 minutes to complete questionnaire and demographic form. I will be the only one in a private room during the audio-visual interview. The estimated time of the interview is between 45 and 60 minutes, one time only. Once the interview is completed, the recording will be transcribed by me, Andrea Wells, verbatim and the recordings will be destroyed. You will not be identified in any way. When the findings from this study are complete, all of the information collected will be combined so that no individuals can be singled out.

RISKS AND DISCOMFORTS

Risk to you for being in the study is minimal. You may experience some emotional discomfort or distress as you talk about certain situations. In the case of this occurring, you may stop participating at any time. There is a potential risk for loss of confidentiality. To protect your confidentiality, your name will not be mentioned during the interview or written on any
questionnaires.

BENEFITS

You may not benefit directly from taking part in this study. However, this study may help us better understand how to support African American women when seeking help to get pregnant.

CONFIDENTIALITY

Your name or any other identifying information will NOT be asked of you during the interview. The recording will be stored on a password protected computer and storage device.

Information obtained about you for this study will be kept confidential to the extent allowed by law. However, research information that identifies you may be shared with the UAB Institutional Review Board (IRB) and others who are responsible for ensuring compliance with laws and regulations related to research, including people on behalf of the UAB School of Nursing and the Office for Human Research Protections (OHRP). The information from the research may be published for scientific purposes; however, your identity will not be given out.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Whether or not you take part in this study is your choice. There will be no penalty if you decide not to be in the study. You are free to withdraw from this research study at any time.

QUESTIONS

If you have any questions or concerns, you may contact Andrea Wells at avgosa08@uab.edu. If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the UAB Office of the IRB (OIRB) at (205) 934-3789 or toll free at 1-855-860-3789. Regular hours for the OIRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday.

APPENDIX D

DEMOGRAPHIC FORM

DEMOGRAPHIC FORM

What is your gender? _____ Female _____ Male _____ Other

What is your age? _____

What racial or ethnic group do you identify? Circle.

White Black Hispanic Other

What is the highest level of education you have achieved? Circle.

Some High School High School Graduate Some College College Graduate

What is your relationship status? Circle.

Single Engaged Partnered/Committed Married

What is your employment status? Circle.

Unemployed Part Time Full Time Self-Employed Other

What type of insurance do you have? Circle.

Uninsured Government Issued Private Insurance

What is your annual income? Circle.

Less than 50k 50k-100k 100k or more Prefer Not Answer

Are you affiliated with any religious group? Circle.

Baptist African Methodist Episcopal (A.M.E) Jehovah Witness

Christian Methodist Episcopal (C.M.E.) Pentecostal/Holiness Catholic

Lutheran Non-denominational Seventh Day Adventist Islam

Non-affiliated Other _____

How long have you had difficulty getting pregnant in years? _____

APPENDIX E

FERTILITY KNOWLEDGE QUESTIONNAIRE

FERTILITY KNOWLEDGE QUESTIONNAIRE

(*Adapted from the Cardiff Fertility Knowledge Scale)*

1. A woman is less fertile after the age of 36 years.

2. A couple would be classified as infertile if they did not achieve a pregnancy after 1 year of regular sexual intercourse (without using contraception).

3. Smoking decreases female fertility.

4. At which phase of the menstrual cycle you are most likely to become pregnant?

a. Just before the period b. Just after the period. c. Halfway between periods. d. Timing in the cycle does not matter d. I don't know

5. Which of these factors is the highest risk for not being able to become pregnant?

a. Older than 35 years of age. B. Stress C. Smoking D. Drinking alcohol

6. These days a woman in her 40s has a similar chance of getting pregnant as a woman in her 30s.

7. Having a healthy lifestyle makes you fertile.

8. A women who never menstruates is still fertile.

9. If a woman is overweight by more than 28 pounds (13kg) then she may not be able to get pregnant.

10. People who have had a sexually transmitted disease are likely to have reduced fertility.

Bunting, L., Tsibulsky, I., & Boivin, J. (2013). Fertility knowledge and beliefs about fertility treatment: findings from the International Fertility Decision-making Study. *Human Reproduction (Oxford, England)*, *28*(2), 385–397. https://doi.org/10.1093/humrep/des402