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African American Women's Experiences and Understanding of Secondary Infertility

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2019

Abstract

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Doctoral Study Submitted in Partial Fulfillment

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Abstract

The purpose of this phenomenological study was to describe the lived experiences of African American women with secondary infertility, defined as an inability to conceive or carry a baby to term after a previous conception. Research on secondary infertility has ignored the prevalence of the condition in African American women. The implications of secondary infertility in African American women have immediate and far-reaching health and psychosocial consequences. African American women rely on interconnectedness and social networks; therefore, social networks and social support served as the key concepts underwriting the study's conceptual framework. Social networks and social support underscore the connection between those needing and those rendering support during stressful life events. The study consisted of 10 African American women ages 18-75 years old, who met the inclusion criteria for the study. Participants completed screening questions, a brief demographic questionnaire, and an interview. Their experiences were captured through first person accounts during one-to-one semi-structured interviews developed through pilot testing. Qualitative analysis yielded four themes: (a) defining family and adjusting to the change in definition of a family; (b) experiences with secondary infertility; (c) psychosocial stressors and supports from friends and family; and (d) treatment and intervention. This research promotes social change by informing clinical practice through access to culturally competent resources, increased responsiveness and policy development promoting timely access to care.

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Dedication

This dissertation is dedicated to those who have supported me throughout my studies: Firstly, the study participants who gave their time and shared their experiences adding to the sparse research on secondary infertility in African American women. Secondly, my Dad, George Clarke for teaching me the value of education and whose hard work in bringing my sisters and I to the United States gave us access to educational opportunities to promote social change in the world. Thirdly, my mother Eula Clarke (1942-1993), who did not live to see my successes, but her passion for me to succeed became a driving force for everything I have done academically and professionally. Fourthly, my sisters, Marcia, Maxine, Patricia, Dimples, Erica and Nadine whose love and strength served as impetus for me to complete my academic goals; also to my two nephews, Jonathan and Ikenna, and my two nieces, Sydney and Jasmin whose futures are uniquely intertwined with my efforts to accomplish my academic goals. Finally, to my husband Kevron who has been my source of support and encouragement during times when I felt defeated and wanted to quit.

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I would like to acknowledge and thank all the study participants for their willingness to share their stories in an effort to empower other women. I would like to extend my sincere gratitude to Dr. Patrick Tschida for his support throughout my classes and finding me the resources I needed to succeed. I would also like to thank Dr. Paige Wermuth for serving on my committee. Special thanks to my family for the informational, instrumental, and emotional support offered to enable me to complete this scholarly endeavor.

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Chapter 1: Introduction to the Study

Introduction

Fertility rates have continuously decreased in the United States. Factors contributing to the decline include higher educational attainment for women, women entering the workplace, greater opportunities for economic success, an increase in the number of couples who delayed child bearing until later in life, and couples deciding to forgo child bearing (Cooke, Millis, & Lavender, 2012; Morgan & Hagewen, 2005). Some women voluntarily choose childlessness; others decide to have two children or fewer, while others struggle to conceive (Rowland, 2007). Infertility is one reason some women are unable to have children. The World Health Organization (2016) defined infertility as a disease of the reproductive system marked by the inability to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse. Experts have identified two types of infertility: primary and secondary infertility. Many researchers study primary infertility because it is easy to identify and quantify; however, secondary infertility, defined as an inability to conceive or carry a baby to term after a previous conception, is studied to a lesser degree (Nachtigall, 2006).

Genetic, environmental, medical, and social factors contribute to secondary infertility (Nachtigall, 2006). These factors create psychological stressors for many women desiring to have additional children (Mosalanejad, Parandavar, Gholami, & Addollahifard, 2014). Most research on infertility focus on White women, directly ignoring its prevalence in minority populations (Nachtigall, 2006). Many would contend that all black women are of the Diaspora, but the term does not include more recent "voluntary" and refugee diasporic populations, such as those from east Africa or the Caribbean. In reviewing the existing literature on the topic, I found very few studies on the causal factors of secondary infertility in African American women. The lack of research is concerning because of the high incidences of morbidity and mortality in the areas of gynecology and reproductive health for African American women (Bower, Schreiner, Sternfeld, & Lewis, 2009). Additionally, studies on White women cannot be extrapolated to African American women because racism and prejudice are inherent to the experiences of African American women in their use of and access to health care services. In addition, there is a disparity in the use of services by minority groups to address underlying infertility issues (Jain, 2006).

Background of the Study

Documenting the prevalence of secondary infertility is challenging because of limited data and how the condition is defined. Researchers estimate secondary infertility rates at 10% globally among women ages 20-44, and less than 9% for the same population in the United States (Mascarenhas, Flaxman, Boerma, Vanderpoel, & Stevens, 2012). However, according to Covington and Burns (2006), secondary infertility rates could be as high as 35%. Secondary Infertility has many definitions in the literature. Researchers have defined secondary infertility in terms of the medical or clinical model (Larsen, 2005). An infertility diagnosis in the medical or clinical model focuses on conception, but does not include carrying a child to term or a live birth. Defining secondary infertility and documenting its prevalence presents a challenge for the population experiencing it and those researching the problem. Superficially, the prevalence of secondary infertility for women of the African Diaspora in developing countries appears less problematic, but its etiology, prevalence, effects, and treatment options are difficult to document (Larsen, 2000). Additionally, few researchers have studied African American women's experiences with secondary infertility. Most researchers have extrapolated their findings based on studies conducted with White women to African American women and by extension to other black women (Feinberg, Larsen, Catherino, Zhang, & Armstrong, 2006), or they have included a very small number of African American women in their studies (Feinberg et al., 2006). Sandelowski (1995) stated that small sample sizes make a study's findings problematic because of the lack of generalizability. Moreover, limited information on African American women's health care issues is insufficient to inform practice in clinical settings and cannot lead to better health outcomes for this population (Feinberg et al., 2006). Thus, I determined that an in depth exploration of the lived experiences of African American women who face secondary infertility was needed to understand the factors that contribute to the condition and the lack of culturally competent services to meet their needs.

Problem Statement

Globally, millions of women struggle with the inability to conceive (Nachtigall, 2006). Infertility is defined as the inability to conceive while engaging in unprotected penile-vaginal sex for 1 year for women between the ages of 15-44 (Chandra, Copen, & Stephen, 2013; Khan, Gulab, & Khan, 2014). According to the Centers for Disease Control (as cited by Chandra et al., 2013), 6.7 million women between the ages of 15-44 struggled with infertility in the United States, but only 9% of those women were affected by secondary infertility between 2006 to 2010 (Mascarenhas, Flaxman, Boerma, Vanderpoel, & Stevens, 2012) . However, these numbers may be an underestimate due to underreporting (Chandra et al., 2013; Khan et al., 2014; Larsen, 2000). According to Covington and Burns (2006), secondary infertility rates could be as high as 35%; moreover, it is estimated that 3-7 % of women experiencing secondary infertility continue to experience subfertility (Irvine, 1998). One factor contributing to underreporting of the prevalence of infertility is the lack of access to medical resources resulting in no diagnosis (Chandra et al., 2013). Other factors include having reproductive organs removed due to other etiologies prior to a diagnosis (Bower, Schreiner, Sternfeld, & Lewis, 2009), making the decision not to have additional children and thus not being aware of existing fertility issues, or the use of contraceptives to prevent conception (Rutstien & Shah, 2004). These women are not only underrepresented in the research, but their absence contributes to the difficulty in identifying the effects infertility has on African American women (Chandra et al., 2013; Jain & Hornstein, 2005; Jain, 2006; Larsen, 1994, 2000, 2005).

Purpose of the Study

The purpose of this study was to describe the lived experiences of African American women diagnosed with secondary infertility in order to give insight to their subjective understandings and to identify any unmet clinical needs. The nature of this study allowed me to identify the epidemiological, clinical, and psychosocial effect of secondary infertility in African American women. It also allowed me to identify their relationships with their social networks and the differences in their experiences. The absence of research on the lived experiences of African American women with secondary infertility translates to a lack of understanding from health professionals, leading to poor treatment outcomes, and lack of trust with the medical community on the part of these women (Gamble, 1997). Therefore, it is important to understand perceptions and experiences of African American women experiencing the phenomena in order to fill the gap in the research, which may lead to marked changes in perception and improved treatment outcomes for the target population, simultaneously promoting social change in the area of reproductive health (Hatch, 1991).

Research Question

RQ: How do African American women describe their lived experiences of secondary infertility?

Conceptual Framework

Social networks and social support were the key concepts in my conceptual framework. These concepts underscore the connection between individuals and those who offer assistance during stressful life events (Magasi & Hammel, 2004). Social networks are webs of social relationships providing supportive services to individuals in need (Berkman & Glass, 2000; Heaney & Israel, 1997). These relationships are sometimes simplistic, consisting of one or two close family members or friends. They can also be complex, comprising of extended family, church groups, social clubs, ethnic groups, and cultural enclaves crossing geographical boundaries with individuals in multiple networks within a network of shared commonality (Berkman & Glass, 2000).

Each social network has a unique culture (Israel, 1985) and is founded on reciprocity for social support rendered in the moment or in the future (Berkman & Glass, 2000). House (1981) and Israel (1985) concluded social networks offer significant benefits to the participants of these networks and encourage continued participation in the networks. Social networks have several structural characteristics, namely: (a) reciprocity, defined as the extent to which resources and support are both given and received; (b) intensity or strength, indicating the extent to which social relationships offer emotional closeness; (c) complexity, marking the extent to which relationships serve multiple functions; (d) density, the knowledge of and interaction between network members; (e) homogeneity, highlighting the extent to which network members are demographically similar; and (f) geographic dispersion, the extent to which network members live in close proximity to the focal person (House, 1981; Israel, 1985).

Social networks meet a variety of individual needs through group identity, adding value and sense of worth to those participating in them. They also serve as buffers from life's normative and non-normative events, and provide access to resources that would otherwise be unattainable (Beckes & Coan, 2011; Berkman & Glass, 2000). Stressful life events are innate to human existence; therefore, having supports to overcome stressors in life requires having personal relationships capable of offering support (Berkman & Glass, 2000). Beckes and Coan (2011) suggested that social networks offer individuals comfort fostering improved health and wellbeing.

Social support is strongly correlated with wellbeing, serving as a safeguard against stressful factors. Individuals receive social support from social networks to which they belong. Social support is characterized by four types of supportive behaviors: (a) emotional support involves shared empathy, love, trust, and caring (House, 1981); (b) instrumental support includes tangible assistance and services rendered (House, 1981); (c) informational support is the provision of advice, suggestions and helpful information (House, 1981); and (d) appraisal is shared information used for self-evaluation (House, 1981). Social support influences behavior through the building of caring, and trusting relationships while maintaining individuals' right to make their own choices (Beckes & Coan, 2011; Cohen & Willis, 1985; House, 1981).

Social support and social networks aren't always supportive and maybe toxic to those receiving support (Cohen & Willis, 1985). Social networks can create obligations causing more stressors instead of alleviating them (Surkan, O'Donnell, Berkman, & Peterson, 2009). The costs of these social relationships are often greater than their advantages (Belle 1982, 1983; Edin & Lein, 1997). It may be more difficult for individuals to extricate themselves from unsupportive networks that are composed of friends, relatives, and neighbors who are also needy (Edin & Lein, 1997; Belle 1983; 1982). Stressful or unwanted social support contributes to and magnifies stressors because it continuously undermines self-determination and self-esteem (Rafaeli & Gleason, 2009).

In the African American culture, many emphasize interconnectedness, respect for traditions, and reliance on social supports from social networks (Odafe, Salami, & Walker, 2017). African American women are more likely to rely on faith-based supports to get them through the challenges in life (Hatch, 1991; Taylor & Chatters, 1986). These women view faith-based supports as sources of comfort, enhanced confidence, and decreased fear of the unknown or the stressor (Ashing-Giwa et al., 2004). Support from families and friends serve as strong buffers from stressors associated with their minority status (Levine, Taylor, Nguyen, Chatters, & Himle, 2015). Relationship building is done in the context of and with individuals who are not friends or blood relatives, but are considered kinship members (Triandis, 1994, 2001). This connection creates a strong level of interdependence and allows for the fluidity of supports to meet various needs, since women of black ancestry experience greater stressors in life when compared to members of the dominant culture (House, 1981; Johnson, 1995).

Discrimination and perceptions of such result in stressors that are positively associated with poor well-being and decreased life satisfaction. Consequently, access to social support from social networks can serve to ameliorate these factors, reduce risk, and promote resiliency (Schonfeld, 1991; Schulz et al., 2000). African American women's access to and use of health care is interwoven with racism and prejudice, which contributes to stressors, hopelessness, learned helplessness, and poor health outcomes (Brown et al., 2000). Given this set of factors, I sought to use the concepts of social networking and social support to understand African American women's lived experiences with secondary infertility.

Nature of the Study

In this study, I used a phenomenological method of inquiry. Phenomenological studies involve small sample sizes to gather more robust data, allowing researchers to explore the individual perspective on the lived experience (Creswell, 2009; Roberts, 2013). Accordingly, in this research, I worked to understand participants' descriptions and accounts of the phenomena for external factors influencing their experiences (see Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). With a phenomenological approach, I captured these experiences through first person accounts during one-to-one structured or unstructured interviews; where themes and meanings emerge that add value for research (Annells, 1996; Tight, 2016).

The phenomenological approach is not without criticism, according to Tight (2016), who, citing Alsop and Tompsett (2006), suggested that a phenomenological approach only shows a narrow view of what has actually transpired, thus adding little empirical information. Tight (2016) also noted that some researchers (e.g., Hazel, Conrad & Martin, 1997) have argued that this research approach is subjected to recall biased. Recall bias can influence data collection, but does not negate the validity of my inquiry in addressing the effects of secondary infertility on African American women who experienced the phenomena.

Definitions

Infertility: The inability of a noncontracepting sexually active woman to have a live birth (Larsen, 2000).

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

Secondary Infertility: Infertility in a woman who has had one child unable to have another (Epstein & Rosenberg, 2005).

Fecundity: The ability to produce healthy offspring (Obeidat, Hamalan, & Clark-Callister, 2014).

Infecundity: The inability to carry and produce live births (Mascarenhas, Chung, Mathers, & Stevens, 2012).

Childlessness: Having no live births *(*Larsen, 2000).

Subfertility: A form of reduced fertility with prolonged time of unwanted non-conception (Gnoth, Godehardt, Frank-Herrmann, Friol, & Freundi, 2005)

Social support: Physical and/or emotional support given by family, kinship relations, friends, coworkers, and others in social networks (House, 1981).

Social network: The people who are identified as providing social support (House, 1981).

Kinship: Blood relatives and non-blood relatives who offer supports of varying kind (Heaney & Israel, 1997).

Socioeconomic status: Social and economic position of women that is based on level of education, profession, and earned income (Jain, 2006).

Parity: Carrying a pregnancy to viable gestational age (Kim et al., 2012).

Assumptions

I made three assumptions in the study. The first assumption was that participants would be willing to share their stories and discuss their feelings and experiences openly and honestly. Discussing health, illness, and health care is extremely personal and emotional for African American women. In the African American community, there is stigma surrounding discussion of health concerns, and there is a level of secrecy and not wanting to share information with outsiders (Ashing-Giwa et al., 2004). Distrust of researchers and the health care delivery systems due to medical experimentation on unsuspecting African Americans has reduced their confidence in research, its outcomes, and benefits (Gamble, 1997). Furthermore, some women may view secondary infertility as a shameful experience, and fertility struggles may not be shared honestly because of the intense shame (Ashing-Giwa et al., 2004). Moving beyond those shameful experiences requires unveiling the factors leading to secondary infertility and demonstrating how shared stories would benefit other African American women by validating feelings and emotions. Moreover, unearthing these factors could compel clinical practitioners and providers to adequately address the health care issues faced by African American women.

My second assumption was that geography may serve as a barrier. I had intended to conduct the study in a semi-rural area where women of African heritage are a small subset of the community and are disperse over a large geographical area. Therefore, being able to locate and recruit participants over this wide geographical area would be difficult for me. Third, I assumed that I may encounter difficulty accessing the target sites of gynecological clinics, churches, and social networks as avenues for recruitment. Gynecological clinics are few and are not always willing to work with researchers because of fear that it would affect them financially. Additionally, these churches may not have a large congregation of African American women, and if they do, they may view this study as invasive and not in line with their Christian values. As a result, they would not allow for recruitment or inadvertently encourage their congregation not to participate. Moreover, the challenge of identifying African American women through social networks or through gatekeepers does not always grant access to the target population. Gatekeepers are difficult to identify in semi-rural areas because of distrust of outsiders.

Limitations

The study had four limitations. The first limitation was that the target population comprised of African American women only. Identifying and recruiting women of African ancestry struggling with secondary infertility required joint efforts with local churches and clinics to identify and refer women to participate in the study. The second limitation was the sample size of the study. The study was slated to include a small number of participants. The small sample size limited generalizability to other women living in similar circumstances. Therefore, the lived experiences of African American women cannot be extrapolated to women of other races and ethnicities.

The third limitation was my use of phenomenological inquiry. Phenomenological inquiry could not provide quantitative descriptions concerning secondary infertility in the target population. Although qualitative studies are able to specifically identify psychological and physiological factors associated with secondary infertility for this study sample, the findings from this study were limited to my interpretations. The fourth limitation was time. The study is in completion of an academic requirement; therefore, the study is time sensitive.

Significance of the Study

There is a gap in the literature on the lived experiences of African American women who struggle with secondary infertility. In this research, participants identified and described the epidemiological, clinical, and psychosocial experiences of dealing with secondary infertility. Across all domains of health, illness, and health care, African American women have the highest incidences of morbidity and mortality (Williams & Mohammed, 2009). African American women are more likely to seek fertility treatments after prolonged periods of trying to conceive, unlike their White counterparts (Feinberg et al., 2006). The earning potential for African American women continues to be less than their White counterparts. Health insurance is tied to income. Having adequate health insurance allows African American women to address issues related to secondary infertility. Consequently, a lack of sufficient income and health insurance contributes to the prolonged effect of secondary infertility (Feinberg et al., 2006). These factors collectively contribute to the epidemiological, clinical, and psychosocial effect of secondary infertility in African American women. In this study, I aimed to provide insight about the challenges specific to African American women and address the lack of information surrounding the issue of secondary infertility in the target population. Additionally, by exploring their lived experiences, I hoped to promote social change in how the problem is addressed and bring awareness to the need for culturally competent interventions.

Summary

Infertility is identified as either primary or secondary in the literature. The research has overwhelmingly focused on primary infertility and less on secondary infertility. African American women struggle with secondary infertility, but their experiences with secondary infertility are not fully documented in research. Studies on secondary infertility in White women or women in developing countries are often extrapolated to African American women. The experiences of African American women with secondary infertility are unique and differ from their White counterparts and women in developing countries.

African American women struggle to address their health concerns because of stigma surrounding secondary infertility. They are also less likely to seek medical services to address secondary infertility due to lack of resources to meet their health concerns. There are other challenges that abound for African American women, as they often do not participate in studies because of the historical distrust of researchers. There is also shame in sharing health concerns with outsiders, even if it is to their benefit. African American women use social networks to help them cope because social networks provides information and support; however, these networks can create psychosocial stressors as well. It is important to understand the effects of secondary infertility and how social networks and social supports impact African American women’s abilities to cope with secondary infertility. Understanding and acknowledging secondary infertility in African American women may change how services are delivered, reduce the negative impact on well-being, and increase life satisfaction. In Chapter 2, I review the literature and its relevance to secondary infertility in African American women.

Chapter 2: Literature Review

Introduction

Secondary infertility limits many women's abilities to conceive a second time. Advances in reproductive health, infertility treatments, and access to timely health care leads to low incidences and prevalence of secondary infertility (Larsen, 2000). However, researchers have not documented the prevalence of secondary infertility for African American women in research studies. In a review of the literature, I found that African American women's experiences with secondary infertility has been minimally addressed, but is largely absent from research. The literature review consisted of reviews of books and scientific peer-reviewed articles on primary and secondary infertility. I use a local public library and the Walden University library to access databases, including: Google Scholar, Academic Search Complete/Premier (EBSCO), JAMA, Science direct, Medline with full text, SocINDEX with full text, Psycho Info, and Education Research Complete. The search terms and key words I used to find studies focused on African American women and their experiences with secondary infertility were *health seeking behaviors, access to health care, health care delivery systems, reproductive health, black women, minority women, African American women, developing countries, developed countries, race, racism, access to health insurance, social support, United States of America, primary and secondary infertility*.

The literature review showed a deficit in the research pertaining to African American women and secondary infertility. Numerous researchers have documented the effects of primary infertility, and to a lesser degree secondary infertility (Chandra et al., 2013; Larsen, 2000; Mascarenhas et al., 2012; Nachtigall, 2006). These studies have focused primarily on the experiences of White women and women in developing countries, making it difficult to extrapolate the findings to African American women (Jain, 2006). Secondary infertility has implications for African American women and their reproductive roles. The lack of research on their lived experiences further contributes to the lack of clinical understanding, improper treatment, and the absence of culturally competent responses to secondary infertility in the population.

Defining Infertility

Words such as sterility, infecundity, childlessness, and subfertility are used to explain infertility and its implications for those affected. There is a marked distinction between infertility and subfertility, but researchers use both terms interchangeably. According to Gnoth et al. (2005) subfertility is a form of reduced fertility with a prolonged time of unwanted non-conception. Infertility, however, is defined as the inability to conceive (Larsen, 2000). Competing definitions of infertility adds to the difficulty in addressing its effect. Analysis by Mascarenhas et al. (2012) identified seven definitions for infertility. The clinical, demographic, epidemiological definitions for infertility address the different ways researchers collect data about the disorder (World Health Organization, 2016). Clinical definitions for infertility framed it as a “disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or regular unprotected sexual intercourse” (Zegers-Hochschild et al., 2009, p. 1523). Or “the inability of sexually active, non-contraception couple to achieve pregnancy in one year” (World Health Organization, 2016). The demographic definition of infertility includes the “inability of those of reproductive age (15-49 years) to become or remain pregnant within five years of exposure to pregnancy” (Rutstein & Shah, 2004 p. 3). A second demographic definition is the “inability to become pregnant with a live birth, within five years of exposure based upon a consistent union status, lack of contraceptive use, non-lactating and maintaining a desire for a child” (Mascarenhas et al., 2012, p. 2). The epidemiological definition of infertility centered on monitoring and surveillance. Therefore, the definition is “women of reproductive age (15–49 years) at risk of becoming pregnant (not pregnant, sexually active, not using contraception and not lactating) who report trying unsuccessfully for a pregnancy for two years or more” (World Health Organization, 2006, p. 63). The clinical and epidemiological definitions are more closely aligned because they involve early detection and treatment as well as surveillance (Mascarenhas et al., 2012).

There is a distinction between secondary and primary infertility (Raque-Bogdan & Hoffman, 2015), but the definitions in the previous paragraph do not address these differences. Primary infertility is the “inability to bear children, either due to the inability to conceive or the inability to carry a pregnancy to a live birth” (Rutstein & Shah, 2004 p. 3). Alternatively, secondary infertility is the inability to bear a child after having an earlier birth (Awartani, Nahas, Al Hassan, Al Deery, & Coskun, 2009; Rutstein & Shah, 2004). Mammo and Morgan (1986) found a correlation between primary and secondary infertility. Primary infertility has a higher incidence than secondary infertility; therefore, researchers use primary infertility as the reference point for those with secondary infertility (Raque-Bogdan & Hoffman, 2015). Yet, women who experience secondary infertility have reported being isolated from those who suffer from primary infertility as well as from those who are fertile (Raque-Bogdan, & Hoffman, 2015). These definitions also exclude the role men play in infertility, consequently presenting infertility as exclusively women's issue. However, infertility distribution shows a different picture. For couples experiencing infertility, the distribution shown by percentages reveal females account for 35% of infertility cases; males account for 30%; 20% stemmed from both males and females; and 15% had causes that were unknown (Poppe, Velkeniers, & Gilnoer, 2007). Other researchers found that 40% of infertility cases are linked to contributing factors from both female and male partners; however, reproductive problems such as ovulatory disorders contributed to 25%, fallopian tube damage contributed to 20%, and uterine or peritoneal abnormalities contributed to 10%, and 30% of infertility cases are unknown (National Institute for Health and Care Excellence [NICE], 2013).

Infertility differs for those experiencing it and for those defining it. A single definition of infertility does not apply to all individuals. Some individuals do not define themselves as infertile unless they want to be parents (Greil, Slauson-Blevins, & McQuillan, 2010). Defining infertility requires a more standardized approach, where exposure, couples' status, contraceptive use, intent and outcome are used as measurements (Greil et al., 2010; Mascarenhas et al., 2012). Thonneau and Spira (1991) proposed regional studies as required for collection of more comprehensive data on the morbidity of infertility. Mascarenhas et al. (2012) analyzed 53 surveys from 26 countries and found exposure, intent, and outcomes to be significant in capturing infertility. The exposure timeframe researchers have used to assess a fertile union led to women being misclassified as infertile if the period of exposure was 1 to 2 years later. Couples' marital status and contraceptive use were used to assess their desire to have children. If the couples' status is the only factor explored, the research would only capture the couple's first and only union resulting in an underestimation of fertility issues, and would ignore subsequent unions that may produce a pregnancy (Mascarenhas et al., 2012).

According to Larsen (1994, 2005) contraceptive use is a strong determinant of fertility. It is difficult to determine the ability to conceive just by the use of contraceptive for many women because, barring the desire to get pregnant, they would use contraceptives if they were available to them (Mascarenhas et al., 2012). Intent, according to Mascarenhas et al. (2012), involves women who intentionally wish to have children and those who do not take precautions to avoid doing so. Women who want to conceive but are unable to become pregnant, and who subsequently change their status to not wanting children must be factored into infertility reporting (Mascarenhas et al., 2012; Rutstein & Shah, 2004). Outcomes refer to the number of live births and must be considered in the data collection along with the etiology of conception, spontaneous abortions, or the progression of pregnancy (Mascarenhas et al., 2012). There is little agreement on defining infertility, its prevalence, and the differences that exist within and across cultures. This influences how health care is delivered and how researchers measures infertility (Gurunath, Pandian, Anderson, & Bhattacharya, 2011). Disagreement in the literature on how infertility is defined and data are collected continues to play a significant role in the ways infertility is reported, how care is sought, and the type of care received.

Global Impact of Infertility

Through the use of family planning programs, men and women can choose the number, timing, and spacing of children. Nachtigall (2006) argued there are two paradoxes that surface regarding fertility. The first paradox is that population growth continues to be a problem, and many populations do not have the resources to sustain themselves. Additionally, women in developing countries are more likely to get married young and have children early, contributing to the population growth (Nachtigall, 2006). Furthermore, these populations sometimes have lower incidences of primary infertility (Larsen, 2000; Nachtigall, 2006). Diagnosing the underlying cause of infertility in women in developing countries is very costly (Belsey, 1976). Data collected using census, vital event registry, interviews with heads of household, and administrative records and surveys of demographic data in sub-Saharan Africa showed how costly using various tools to gather information can be for researchers (Belsey, 1976). Moreover, data are subject to limitations because some data may be inaccurate or incomplete because of how the condition is defined (Larsen, 2000, 2005;Belsey, 1976).

There are also other factors contributing to infertility in developing countries. These factors include sexually transmitted infections (STIs) such as pelvic inflammatory disease, chlamydia, gonorrhea, and syphilis (WHO, 2013; Belsey, 1976). Other factors such as mumps, leprosy, toxoplasmosis, and other infectious organisms are contributors to infertility in developing countries (Belsey, 1976). Cultural practices such as female genital mutilation, genetic disorders such as sickle cell, hormonal changes such as thyroid disease or goiter, and poor nutrition lead to irregular periods or amenorrhea in some women (Belsey, 1976;Verma, Sood, Juneja, and Kaur, 2012). In these cases, it is sometimes difficult to point to one factor that affects infertility.

The second paradox is low birth rate in aging populations. Western countries have lower fertility rates and are unable to sustain the current aging population (Revonta et al., 2010). The decline is attributed to women entering the work force, couples choosing to have fewer children, couples marrying later in life, choosing not to have children altogether, and having access to safe and legal abortion (Revonta et al., 2010). In the United States, fertility rates are low, many have ideas about what these rates are, but others suspect that the rates are underreported. The documented infertility rate is an underestimation, and the only accurate figures consist of recent efforts to track women who have enrolled in studies (Thoma et al., 2013). In short, infertility rates are a subject of contention in the research. Winkelman, Katz, Smith, and Rowen (2016) suggested that infertility rates are known, and they postulated that 6.7 million women of reproductive age in the United States are affected by infertility. Their data showed 8.5% of the population affected in 1980 compared to 11% in 2010 (Winkelman et al., 2016).

The decline in fertility rates stemmed from fewer attempts to have children; however, the rates of infertility have increased considerably and are magnified due to fluctuation in population growth in some areas and its decline in others (Mascarenhas et al., 2012). Between 1990 and 2010, primary and secondary infertility prevalence were estimated from data collected from surveys. Mascarenhas et al. (2012) reported that women from 190 different countries and territories were interviewed, but the study focused primarily on female respondents, even though in coupled relationships men and women could be equally responsible for the couple's infertility. Mascarenhas et al. (2012) reported significant differences in the rates of primary infertility and secondary infertility prevalence among women in Latin America/the Caribbean, Eastern Sub-Saharan Africa, and Central Sub-Saharan Africa.

The effects of infertility are both personal and societal. Suffering with infertility is considered a personal experience and women grappling with infertility keep silent about their struggles (Nachtigall, 2006). Many women struggling with infertility try to cope with the psychological, physical and interpersonal challenges alone (Obeidat et al., 2014). Infertility is not only experienced privately for these women, but leads to societal consequences. In many cultures, fertility is indicative of economic prosperity and familial survival. In developing countries, having children guarantees a steady workforce (Belsey, 1976). Women are often blamed for their inability to conceive a child notwithstanding the fact that infertility is not endemic only to women (Nachtigall, 2006; Rouchou, 2013).

Infertility affects women's statuses in their communities in developing countries (Rouchou, 2013;). Moreover, the ability to conceive offers a higher status to many women and inability to conceive is a tool to shame other women in the same community (Belsey, 1976; Rouchou, 2013; Schmidt, 2009). Women who had previously conceived, but aborted the fetus, saw infertility as a punishment from God. Women deemed marriageable would have their dowry; price negotiated if they were barren (Belsey, 1976). Many women have reported experiencing intimate partner violence, community violence and disrespect due to their inability to conceive (Nachtigall, 2006). The effects of infertility from a societal level only added to the shame and guilt many women already carry; therefore, it contributed to an unwillingness to seek appropriate medical intervention or openly discuss the challenges of being infertile.

Factors Contributing to Female Infertility

Too many known and unknown variables make it difficult for direct causal relationships to be established for all infertility cases. Infertility can occur at any point during the child bearing years (Larsen, 2000). Factors most implicated in secondary infertility are advanced maternal or reproductive age, structural complications, Asherman Syndrome, uterine fibroids and smoking. These factors are studied in relation to other contributing factors that compound the diagnosis and treatment for secondary infertility.

Advanced maternal age is easiest factor to identify with regards to secondary infertility. Emphasis on advanced maternal or reproductive age ties fertility or infertility to women, making it a women’s only issue (Balasch & Gratacos, 2011). Women who delay child bearing until later in life place themselves and their fetus at risk for complications common in women conceiving in later childbearing years (Cooke, Mills, & Lavender, 2012). There is an increased risk of miscarriage, ectopic pregnancies, elevated maternal morbidity stemming from hypertensive disorders and gestational diabetes for women conceiving later in life (Mills & Lavender, 2011). Most women are born with the total number of oocytes they will have over the course of their lifetime, and as women age, the number of oocytes decreases. Advanced maternal age contributes to decreased oocytes production and release leading to decreased fertility for older women (Balasch & Gratacos, 2011; Mills & Lavender, 2011).

Women often delay child bearing until their thirties or forties (Revonta et al., 2010). This is also the time when they grapple with hormone imbalances which can contribute to infertility (Poppe, Velkeniers, & Glinoer, 2007). Hormone imbalances are sometimes caused by diseases and are masked by other chronic illnesses such as diabetes, depression, and autoimmune diseases (Poppe et al., 2007). Hormone imbalances contribute to hypothyroidism, which affects sexual development and contributes to amenorrhea and infertility. Moreover, "hypothyroidism affects fertility due to anovulatory cycles, luteal phase defects, hyperprolactinemia and sex hormone imbalance" (Poppe et al., 2007, p. 2079). Hypothyroidism also affects women's ability to conceive and if conception is successful, the developing fetus may be deprived of iodine (Valvekar, Lakshmi, & Kumar, 2016). In a case-controlled study of 120 women ages 23 to 29, who struggled with primary and secondary infertility, the cases had higher incidences of hypothyroidism when compared to the control group of women (Valvekar et al., 2016). Verma et al. (2012) suggested that women suffering from hypothyroidism are able to conceive 6 weeks to one year after taking the hormone thyroxine.

Structural complications such as pelvic adhesions caused by endometriosis, myomectomies and other abdominal surgeries are also contributing factors to secondary infertility (Balasch & Gratacos, 2011; Mills & Lavender, 2011). The partial or complete obliteration of the uterine cavity or trauma to the endometrium leads to Asherman syndrome (Yu, Wong, Cheong, Xia, & Li, 2008). Recurrent pregnancy loss and irregularities in the menstrual cycle are attributed to Asherman Syndrome. Klein and Garcia (1973) identified 11 patients who struggled with the disorder. Of the 11 participants, only four participants conceived after medical intervention. Yu et al. (2008) completed a retrospective review of the medical charts of four women between the ages of 35-38. The review revealed participants suffered secondary infertility because of Asherman syndrome. Medical intervention in the form of preoperative evaluation, intraoperative and postoperative management helps to correct the condition (Yu et al., 2008). The small sample sizes of the study may reduce generalizability, but the results speak to the effect Asherman syndrome has on fertility outcomes.

There is a strong correlation between smoking and an increased risk for infertility in women of childbearing age (Revonta et al., 2010). Based on the study consisting of 2112 women, less than a one-third of these women were smokers. Researchers found infertility to be a direct result of heavy smoking; however, individuals who were light smokers appear to have the same probability of conceiving when compared to non-smokers (Hassan & Killick, 2004). Research by Gaur, Talekar, and Pathak (2010) found no safe smoking exposure level, every level of exposure to smoking whether primary, secondary or tertiary, places women of child bearing age at risk for infertility. Women are encouraged to stop smoking upon conception, whereas efforts to eliminate smoking prior to conception continue to be a public health challenge (Bolumar, Olsen, & Boldsen, 1996). Poor outcomes in assisted reproductive therapy are linked directly to smoking because it reduces the effectiveness of these therapies and compound infertility (Revonta et al., 2010).

Adenomyosis is the growth of the endometrium into the myometrium; a benign condition that is only diagnosed through a hysterosalpingogram (HSG) (Al-Safi, Russ, Post, & Polotsky, 2013). The effect of Adenomyosis on fertility is based on one case study. According to Al-Safi et al. (2013), HSG is the only technique to diagnose cases of Adenomyosis. Its prevalence is found in approximately 5% to 70% of women (Graziano et al., 2015). Adenomyosis leads to menorrhagia, dysmenorrhea and subfertility (Li, Liu, & Guo, 2014). Infertility in women with Adenomyosis stemmed from the thickening of the uterine lining. Although the thickening of the lining helps with implantation of a fertilized egg, thickening of the lining caused by Adenomyosis reduces implantation of a fertilized egg making it difficult for the egg to attach and grow inside the uterus (Campo, Campo, & Benagiano, 2012).

In a case controlled study, Wolf, Daling, and Voigt (1990) examined the relationship between cesarean delivery and postpartum complications. They argued postpartum infections may contribute to secondary infertility to a lesser degree for vaginal delivery, but increases exponentially for cesarean deliveries. A review of the experiences of 61 cases and 343 controls showed women of similar education and income had success in conceiving after treatment for postpartum infections (Wolf et al., 1990). The research also found no correlation between cesarean delivery leading to postpartum infections and secondary infertility, but these researchers attributed their findings to early detection and treatment. They also highlighted that women who had successfully conceived were not motivated to participate in infertility treatment.

Cesarean delivery and vaginal births may affect women’s willingness to have more children. Kjerulff et al. (2013) suggested the mode of birthing a child may correlate to secondary infertility in women. They recruited women from various locations between

January 2009 and April 2011. A total of 3080 women were recruited, but 74 of the study participants dropped out of the study. Most of those in the attrition group were younger, less likely to have health insurance, and lived in urban areas. Similarities between the participants included race, ethnicity, age ranges from 18-35, primiparous, currently carrying one child, spoke Spanish or English and would deliver at a Pennsylvania hospital (Kjerulff et al., 2013). The hypothesis testing to determine whether women who deliver by cesarean section were less likely to have more children when compared to those who deliver vaginally was not supported. Additionally, Kjerulff et al. (2013) argued women who delivered by cesarean section were more likely to decide to have no further children after child birth for reasons associated with the mode delivery was also not supported. The study was limited in that it recruited individuals of higher socioeconomic status, which translates to access to medical treatments to address underlying issues. The study was not a population based study, but the results showed that mode of delivery did not affect whether women were more likely to have one child or have a greater number of children. This study did not speak to infertility, but highlighted women's desire to give birth and have children even if it is only one child.

More than 80% of African American women are diagnosed with uterine fibroids, but uterine fibroids are not routinely screened for by gynecologists, unless they produce symptoms (Chen, Buck, Courey, Perez, & Wactawski-Wende, 2001; Eltoukhi, Modi, Weston, Armstrong, & Stewart, 2014). Estimates placed fibroid tumor-related care as costing over nine million dollars in the United States (Eltoukhi et al., 2014). Hospitalizations, hysterectomy, and myomectomy rates continues to be highest among

African American women (Wechter, Stewart, Myers, Kho, & Wu, 2011; Wu, Wechter, Geller, Nguyen, & Visco, 2007). Uterine leiomyomata affected African American women three times more than it affects their White counterparts resulting in African American women needing hysterectomies which also contribute to infertility (Wise et al., 2004, 2009).

Additional studies showed African American women have larger and more aggressive fibroid tumors at younger ages. The average age for African American women to be diagnosed with fibroids is 31 versus 37 for White women (Huyck et al., 2008). Outcomes and response to treatment still shows a difference by race, with African American women having more invasive procedures with poorer outcomes (Abenhaim, Azziz, Bartolucci, & Tulandi, 2008). Essence magazine was used as a recruitment tool to conduct a prospective study for African American women to determine factors contributing to uterine fibroids. The study consisted of 64,500 participants ages 21-69. Many of these women had previously had children, but the factors explored such as menarche, parity, and age of having first child, did not contribute to uterine fibroid for the study participants (Wise et al., 2004).

Uterine fibroids contribute to infertility by leading to abnormal uterine contractility, elongation of the uterine cavity, and distortion of uterine vascularization (Bulletti et al., 2004). Additionally, women with fibroids are at high risk for preterm labor, placenta previa, postpartum hemorrhaging and neonatal morbidity (Vergani et al., 1994, 2007). Other risk factors due to uterine fibroids include spontaneous abortion and pregnancy loss in the first term (Cook, Ezzati, Segars, & McCarthy, 2010). Women with a history of uterine fibroids also presented with issues of infertility (Hasan, Arumugam, & Sivanesaratnam, 1990) and obesity (Huyck et al., 2008). Women with obesity were almost three times more likely to have challenges with fertility than women with lower body mass index (Hassan & Killick, 2004).

Factors Contributing to Male Infertility

Infertility is not just attributed to women, because male varicocele contributes to secondary infertility at higher rate than it does for primary infertility. Men's participation in reproductive health involves their willingness to see themselves as partners in the process with their spouses as well as clients in need of reproductive services (Mundigo, 1998). A difference exists in the cost of treating contributing factors for secondary infertility in men and women. It is more cost effective to treat male factors contributing to secondary infertility (Goldstein, 1993). Male infertility is affected by occupational hazard or toxins, testicular tumors, and lifestyle choices including diet, drug use, unprotected sexual activity, alcohol consumption, smoking, obesity and diseases such as varicocele, and/or hypospadias (Gaur et al., 2010; Hassan & Killick, 2004; Lagana, Vitale, Laconianni, Gatti, & Padula, 2016).

In a prospective study of 289 male respondents, the researcher categorized the group as nonsmokers and non-alcohol users, alcohol users but nonsmokers, and smokers but non-alcohol users. Gaur et al. (2010) found that alcohol use reduced testosterone production, contributing to impotence and compounded secondary infertility. The research also showed that smoking, whether heavy or light contributed to poor sperm development and limited sperm motility, contradicting Hassan & Killick (2004) results that light smoking has less of an impact on fertility rates.

Hypospadias is a congenital abnormality, where the opening of the urethra is on the underside of the penis, and sperm is deposited in higher areas of the vagina, than is needed for conception (Pfeil & Lindsay, 2010). It affects 10% to 15% of males (Pfeil & Lindsay, 2010). The disorder affects sperm count, sperm deposits and quality differently. Semen count and sperm motility may decline as men age, but does not limit men's ability to reproduce (Balasch & Gratacos, 2011). Oligozoospermia is defined as low concentration of sperm, with low motility and abnormalities affecting men's fertility (Jungwirth et al., 2015; Pfeil & Lindsay, 2010). There are men whose ejaculates contain only semen; this is defined as azoospermia (Jungwirth et al., 2015; Pfeil & Lindsay, 2010). Some men also experience healthy sperm count and adequate semen for their sperm, but due to blockage along the ejaculatory duct viable sperms are unable to pass to the female during sexual activity contributing to fertility problems (Jungwirth et al., 2015).

Male infertility is also affected by retrograde ejaculation. Men who have spinal injury have anejaculation (Jarrow et al., 2011). Prostatic cysts in most men do not produce symptoms, but the enlarged cysts obstruct the seminal vesicles causing hematopsemia, low ejaculation and infertility (Zhang et al., 2011). Transurethral unroofing and laparoscopic excision are two procedures to remove prostatic cysts from men at risk for infertility. These surgeries afford males with infertility and their spouses to the ability to conceive within one year (Zhang et al., 2011). The cost of treatment is a significant barrier to seeking treatment for fertility services. The study did not highlight the cost for infertility treatment for men with these health concerns.

Healthcare Cost of Infertility

The health care delivery system in the United States offers extensive fertility treatment services, through the provision of health insurance and medical personnel; however, those options are not available to all women due to many social and cultural barriers (Larsen, 2000; World Health Organization, 2006). In some areas where access exists, the costs are exorbitant; limits on income or lack of income impede women's ability to use these resources (Larsen, 2000). The cost for infertility treatment for men is lower than the cost of infertility treatment for females; it is also less invasive (Çayan, Shavakhabov, & Kadioğlu, 2009).

Evaluation of infertility requires working with both men and women and exploring the factors that may contribute to infertility. The methods of evaluation for infertility can be invasive and impersonal serving as a deterrent (Davis, Hall, & Kaufmann, 2007). Davis, Hall and Kaufmann (2007) suggested in order to evaluate sperm viability, a urologist or fertility specialist must ask men to abstain from sex for 2 to 6 days in order to analyze sperm PH, sperm concentration, motility and total numbers. This evaluation must be repeated in three months if the results are abnormal. Female ovulation evaluation included a menstrual history, serum progesterone, and uterine luteinizing hormone and HSG test for the uterine cavity and the tubal patency (Davis, Hall, & Kaufmann, 2007). These procedures are invasive, requiring multiple visits to different doctors or specialists, and are also very costly.

Availability of infertility treatment often plays out in both private and political domains. Some national health policies advance fertility treatments, but state governmental interferences may limit access to certain types of infertility treatments; albeit infertility is acknowledged as a medical condition (Nachtigall, 2006). The newly implemented Affordable Health Care Act faced strong opposition and states had more autonomy in deciding infertility treatments (Devine, Stillman, & DeCherney, 2014). Not all states have policy mandates to provide treatment for infertility. States such as Massachusetts, Maryland, Connecticut, Rhode Island, Arkansas, California, Hawaii, Illinois, Louisiana, Montana, New Jersey, New York, Ohio, Texas and West Virginia have some mandates in place requiring employers to offer some type of infertility benefits either as a group or to the individual (Devine et al., 2014). California and Texas offer group insurance where infertility treatment is centered on diagnosis, but not on treatment. Arkansas, Connecticut, Hawaii, Illinois Maryland, Massachusetts and New Jersey require coverage for In Vitro Fertilization (IVF), and Hawaii only covers one cycle of IVF (Devine et al., 2014). Moreover, the inconsistencies in coverage among the states having mandated policies serve as a barrier to infertility treatment.

A national survey of family growth for the period of 1982 to 2002 examined "prevalence of infertility and impaired fecundity, the use of infertility treatment and how infertility treatment is affected by state laws mandating infertility insurance benefits." (Bitler & Schmidt, 2006, p. 854). The study was inclusive of women who were married or cohabiting and had been unable to conceive for 12 months or more. The results showed that these women did not benefit from the mandates for insurance. In fact, these women were 29% less likely to access and use infertility treatment. Bitler and Schmidt (2006) found no difference in education and the desire to use infertility services. Additionally, low health care access and low utilization continue to plague African American women, where there is less access to diagnostic and therapeutic interventions (Chandler & Monnat, 2015).

A study of 1315 couples using IVF treatment over a six-year period showed that women who were younger than 35 had better opportunities to conceive and carry children long term than those who were older. Women with secondary subfertility problems were 1.4 times less likely to be able to conceive and carry to term (Stolwijk, Wetzels, & Braat, 2000). Women who are 35 and older continue to spend excess funds on services that may not yield the desired outcomes. The median income for a USA household is $47,845, most IVF costs over $1200 which is a significant amount of that income (Chow & Mahalingaiah, 2016; DeNavas-Walt, Proctor, & Smith, 2007; Smith et al., 2011). IVF is not covered by Medicaid; as a result, low income women who have Medicaid cannot use the insurance to cover fertility treatment (Usha, Salganicoff, Stewart, Cox, & Doamekpor, 2009). Financial factors affecting fertility only comes into play for some uninsured or underinsured women after the third IVF treatment; as a result, financial factors are not reasons for some couples to decrease the number of IVF treatments (Davis, Hall, & Kaufmann, 2007). Jungheim (2015) findings contradict those results because the cost of continuing IVF after the initial IVF failure is a deterrent. The success of IVF and other fertility treatments increases with multiple attempts (Jungheim, 2015; Smith et al., 2011); reducing the number of eggs implanted during each IVF cycle may reduce its failure and the cost associated with treatment (Jungheim, 2015). Whether there is success or failure with IVF, women can only access those treatments through insurance or in states where reproductive health laws are mandated.

A cross-sectional review of medical charts and patient surveys found that women who were not sure of the amount of coverage offered by their insurance or women without insurance were significantly affected by type of fertility treatment sought, if at all (Jones, Gary, & Liu, 2012). Women seeking fertility treatment fit a particular criterion. These women are older, married, have more disposable income, reside in urban areas with access to fertility treatment (Kessler, Craig, Plosker, Reed, & Quinn, 2013; Nachtigall, 2006). Having access to disposable income can have a downside too. In a study of 391 women, where $2,500 to $45,000 was spent on fertility treatment, the pregnancy rates remained relatively constant. Expenses below $2,500 and above $45,000 showed an inverse relationship with fertility treatment success (Smith et al., 2011; Wu, Odisho, Washington, Katz, & Smith, 2014). Even so, women who do not seek treatment are usually poor and of a minority status (Chandra & Stephens 2010). Limited access and few resources are barriers to gaining access to proper healthcare (Chow & Mahalingaiah, 2016). The financial burden of paying for fertility treatments forces many to forgo engaging in treatment (Jones, Gary, & Liu, 2012). The cost of fertility treatments served as a deterrent to seek services as the financial burden to seek services and pay for those services is too great.

Access to fertility treatments decreases the risk of unsafe treatments, however when cost continues to be a barrier, women were less likely to use those services (Boulet et al., 2015; Chow & Mahalingaiah, 2016). Inaccuracies exist about cost being the only deterrent for African Americans use of fertility treatment. African American women face a number of complex and convoluted issues regarding access, and use of fertility treatments. African American women are less likely to use fertility treatments, than their White counterparts because of poorer outcomes (Misser, Seifer, & Jain, 2011; Sharara & McClamrock, 2000). Concerns about poor pregnancy outcomes such as multiple births, spontaneous abortions, ectopic pregnancies and birth defects worry African American women seeking fertility treatment services (Misser, Seifer, & Jain, 2011).

A cross sectional, self-administered survey found that African American women attempted to conceive 20 months longer, traveled at least 19 miles to get to a fertility clinic, had difficulty leaving work or getting time off and could not find culturally competent medical doctors to address the sensitivity of dealing with secondary infertility (Misser, Seifer, & Jain, 2011). African American women were more likely to self-refer to fertility services where as their White counterparts were referred by friends and family. They were more likely to not be informed about the types of services, the risks involved and they were also more likely to encounter medical personnel bias towards them which served as significant barriers (Armstrong & Plowden, 2012; Misser, Seifer, & Jain, 2011).

Psychological Impact of Infertility

The effect of infertility leads to many psychological factors and may exacerbate mental health concerns. Infertility is a reproductive health indicator for women who are interested in conceiving, but unable to do so. Women face unnecessary scrutiny with regards to fecundity. Obeidat et al. (2014) argued sometimes men are excluded in the role they play in infertility; however, women are more likely to believe the onus of infertility lies with them (Raque-Bogdan & Hoffman, 2015). This underscores the fact that some women's identity is tied to having children (Schmidt, 2009). The ability to conceive and bear children is critical to their self-worth and value.

The common theme that emerged from the study by Raque-Bogdan and Hoffman (2015) was the concept of "missing motherhood". Of the missing motherhood concept, themes and subthemes that emerged are martial stresses, feelings of social oppression, experiencing depression and disappointment, have treatment associated with difficulties of conceiving, appreciation and support from friend and family and using coping skills (Schmidt, 2009). Women re-examining their role of becoming parents had greater personal distress than their partners; however, active and passive avoidance was used by the couples to deal with loss of their role in having in a family (Peterson et al., 2009). An inability to have children has psychological effect on some women's self-esteem. Loss of self-esteem, meaning, importance of life, and failure to fulfill the role of a mother brings feelings of personal distress for these women (Ashing-Giwa et al., 2004; Schmidt, 2009). For many women, relationships are important for informational and instrumental supports. Secondary infertility can lead to isolation from those supports for many women thus magnifying the problem and creating despondency (Costello, 1982). In a study of 449 women, the lack of intimacy with spouse or significant others led to depression (Costello, 1982). Schmidt (2009) citing Greil (2007) stated that infertility led to strain on some marital relationships as well as other relationships important to women.

Conversely, infertility provided marital benefits for some couples. A prospective cohort study of 2250 people starting fertility treatments and a sub-cohort of 816 people unsuccessful with treatment found some couples had marital benefits as infertility also strengthened marital relationship and did not always lead to marital discord or distress (Peterson, Pirritano, Christensen, & Schmidt, 2008; Schmidt, Holstein, Christensen, & Biovin, 2005).

Women in other countries also experience similar psychological challenges stemming from secondary infertility. Australia has an adoptee registry which affords women the option to find their children who have been adopted. Andrews (2010) stated that women who have subsequently given birth did not use the registry to find their children given up for adoption. Conversely, women with secondary infertility were more likely to use the registry to initiate contact with the children given up for adoption. These women believed relinquishing a child affected their ability to have another child. This lack of accomplishing the social role of being a parent again triggered psychological distress, stress and low self-esteem (Greil, 1997; Greil, Slauson-Blevins, & McQuillan, 2010).

It is estimated 40% to 60% of women in Australia who relinquished children to the foster care system or through adoption do not go on to have any other children (Andrews, 2010). A three-year analysis from 2003-2006 by Andrews (2010), revealed women who gave up a child and struggled with secondary infertility experienced double losses. Many of these women attended support groups where they connected with other women about the uniqueness of their losses. Many of the women acknowledged very little support in the community either for women who gave children up for adoption or for those with secondary infertility. Public perceptions of the causes of infertility and the direct and indirect consequences of infertility issues limited their ability to seek out additional resources to deal with their grief. Andrews (2010) reported many of these women did not feel connected to the motherhood experiences or they were not viewed by their contemporaries as mothers.

Women experiencing infertility report "negative identity, sense of worthlessness and inadequacy, a feeling of lack of personal control, anger and resentment, grief and depression, anxiety and stress, lower life satisfaction, envy of other mothers, loss of the dream of creating, 'the emotional roller coaster' and sense of isolation" (Griel et al., 2010, p.5). A study of 266 infertile women in the USA who did not have children and had not undergone any treatment or women who had one live birth, but did not have any known fertility challenges showed less distress when compared to their counterparts who had fertility treatments (Greil, McQuillan, Lowry, & Shreffler, 2011). Some studies revealed no correlation between emotional adjustment and the time spent undergoing infertility treatments (Fekkes et al., 2003; Lowyck et al., 2009). However, infertility is directly linked to the distress women face when diagnosed with infertility and/or undergoing infertility treatment (Greil, 1997). The amount of stress women experience before, during, and after treatment affects them in multidimensional ways. Loss of hope, the treatment itself, and the unsuccessful outcome of infertility treatments created distress for women (An, Sun, Li, Zhang, & Ji, 2013). Spontaneous abortion can accompany infertility treatments and create more distress (Verhaak, Smeenk, Van Minnen, Kremer,

& Kraaimaat, 2005). Emotional distress has been cited as the primary reasons for many women not continuing infertility treatments after being highly motivated to start treatment (Benyamini, Gozlan, & Kokia, 2005; Brandes et al., 2009; Lok et al., 2002; Moura-Ramos, Gameiro, Canavarro, Soares, & Almeida-Santos, 2016).

There is a direct link between the psychological distress and the success of an IVF (Quant et al., 2013). A study of 89 female patients and 77 of their partners, revealed a lack of support from others when dealing with the stress of undergoing IVF (Quant et al., 2013). Women struggling with infertility either isolate themselves or relentlessly seek out treatment compounding the problem (American Society for Reproductive Medicine, 2014). In a study of 52 women and men, Pottinger et al. (2006) found women were less likely to share their challenges with infertility and often engage in self-blame. A second study of 308 women, demonstrated that women who did not have any children were more depressed than those who had children and were struggling with secondary infertility (Epstein & Rosenberg, 2005). Emphasis on having children for many women heightened their distress and led to isolation and self-loathing (Andrews, Abbey, & Halman, 1992; Epstein, & Rosenberg, 2005). Women's self-loathing and isolation also affected the strength of their marriages. Marriages served as buffers for emotional distress and infusing the marriage with distress reduces its ability to withstand stress for some couples (Andrews et al., 1992). Many couples who ascribe a larger role in becoming parents experienced more distress due to treatment regiments, and the disappointments faced from poor outcomes (Moura-Ramos et al., 2016).

Tension, anxiety, depression, self-reproach, and suicidal ideation are strong emotions women experience because of the inability to conceive (Mosalanejad, Parandavar, Gholami, & Abdollahifard, 2014). A study of 23 participants identified spirituality as one way to increase hope about conceiving, other participants use shrines and visits with spiritual leaders to help them cope (Mosalanejad et al., 2014). Many of the infertile women use family prayers and support from their families to help them cope at home and sustain their motivation to continue treatment. The grieving process is overwhelming for these women. The high cost, low success, and lack of access to fertility treatment facilities decreased the hope for some women (Mosalanejad et al., 2014).

Women should not only focus on hope, but have self-compassion to mitigate the shame associated with the inability to conceive (Galhardo, Pinto-Gouveia, Cunha, & Matos, 2013). A study of 100 fertile couples and 40 couples with infertility revealed higher levels of psychological distress for those unable to conceive (Galhardo et al., 2013). Self-compassion served as a strong mitigating factor for psychological distress, reducing the effects of shame and stress caused by infertility related diagnosis (Galhardo et al., 2013; Neff, 2008). Fostering self-compassion can be difficult for many women. Feelings of shame, low education, economic stressors and stresses from roles in life affects their ability to seeking mental health services geared towards teaching self-compassion (Copeland & Snyder, 2011; Ward, Clark, & Heidrich, 2009).

African American women and White women may experience similar psychological effect because of secondary infertility. Research on the issue is sparse.

What is known is that African American women are overwhelmingly unable to access care because of their minority status (Koepke, 2007). Having a minority status allows less access to quality services to meet health care needs (Gamble, 1997). Moreover, African Americans still grapple with racism, which creates unique psychological, social and emotional consequences (Odafe, Salami, & Walker, 2017). In addition, the stigma surrounding the use of mental health services to address underlying mental health concerns affects the wellbeing of the African American community (Ward, Clark, & Heidrich, 2009; Ward, Wiltshire, Detry, & Brown, 2013). These factors compound the issues African American women face in accessing, seeking and using services to address the psychological effects of secondary infertility.

Historical Perspective of Health Care for African American Women

A deep distrust exists between the African American Community and medical professionals, stemming from the historical experiences of African Americans (Humphrey, 1973). As a result, low participation in clinical trials and poor health outcomes continues to affect this population. The reproductive history for African American women is enthralled in slavery, racism and prejudice that continue to pervade today's society (Gamble, 1997). Researchers point to the Tuskegee Syphilis Experiment as a purported argument for African Americans low use of medical services and research study participation (Gamble, 1997). Between 1932 and 1972, 600 African American Sharecroppers in Alabama participated in the Tuskegee Syphilis study conducted by the U.S. Public Health Service. These men were injected with syphilis, so researchers could track the natural progression of untreated syphilis, despite the availability of penicillin

(Gamble, 1997; Schiebinger, 2017). Although this experiment was a horrific act against African American men, the distrust of health care professionals began long before the Tuskegee Syphilis Experiment.

During slavery, African Americans were easy targets for medical experimentation due to the overwhelming assumption that black people were property and medical information gained from the exploitation of the "Negro bodies was applicable to Whites" (Savitt, 1982, p. 332). Because of African American slave status, they lacked the economic power to protect themselves. "Slaves found themselves as subjects of medical experiments because physicians needed bodies, because the state considered them property and denied them the legal right to refuse to participate" (Gamble, 1997, p. 1774). The exploitation did not only occur when slaves were alive, but also when they died. Many African American burial sites were desecrated (Gamble, 1997). Bodies of deceased African Americans were dug up, and sold to medical schools in the North to advance medical science (Humphrey, 1973).

The extent of medical experimentation on African Americans is not known (Gamble, 1997). What is known is that African American women were not excluded from this exploitation. Dr. J. Marion Sims' graphic account of his experimentation on Lucy, Betsy and Anarcha, three Alabama slave women, showed the breadth of exploitation African American women endured (Schiebinger, 2017; Sims, 1984). His experiments on these women fine-tuned surgical procedures to repair vesiovaginal fistulas. Dr. J. Marion Sims sent letters to their masters informing them, they would incur no cost if he experimented on these women (Sims, 1884). African Americans strongly believed then, as they do now, that their lives are devalued by the dominant group in society. This belief played a critical role in their relationship or the lack thereof between the African American community and the medical community (Cary, 1992; Gamble, 1997). The prevalence and incidence of diseases along with high morbidity and mortality rates for African Americans are evidence of the deep distrust between the two groups (Cary, 1992; Gamble, 1997). The distrust of health care professional is a historical legacy for African Americans, not easily erased and has continued implications for the health of African American women.

Implications for African American women

The working poor are categorized as individuals who work full time, but do not earn enough to care for their families. Single mothers and members of different minority groups fall into this category (Gilbert, 2003). Some African American women belong to the working poor category, even if they are a part of a two income household, and are less able to participate in or access resources (Koepke, 2007). Income is tied to adequate employment which offers access to insurance. When these factors do not align, they become a deterrent for African American women to access fertility treatment (Smith et al., 2011). Jain (2006) argued that income is a strong predictor of individual's access to fertility treatment. The incomes of minority groups such as Hispanics and African Americans are substantially lower than their White and Asian counterparts (Hao, 2004; Painter 2013). Income is tied to access to health care and by extension these women are less likely to access fertility treatment (Culley, Hudson, & Van Rooij, 2009).

Similarly, socioeconomic disparities serve as a strong predictor of health outcomes. Socioeconomic status is measured by income, social status, and occupation (Dutton & Levine, 1989; Schulz et al., 2002). Controlling for socioeconomic status does not eliminate the poor health outcomes (Williams & Collins, 1997). Poorer health outcomes continue for African American women at the lower end of socioeconomic status than those who benefit from a higher socioeconomic status. Yet health outcomes are still not favorable for African American women in higher socioeconomic status (Hibbard et al., 2008). African American women in the higher socioeconomic status are more likely to seek out health information and engage in advocacy for their health care needs (Hibbard et al., 2008); however, they still fair far worse than their White counterparts in both higher and lower socioeconomic brackets (Goza, Stockwell, & Balistreri, 2007; Navarro, 1990).

Education empowers women of lower socioeconomic status by increasing knowledge, skills, and resources, enabling them to navigate the choices related to health care, and health care utilization to address secondary infertility (Monnat, 2014). There is limited research on the impact of secondary infertility, racial disparities in health care and health care utilization in African American women (Feinberg et al., 2006). Utilization is a barometer for measuring infertility. Since African American women are already disenfranchised, their utilizations rate will be low (Culley, Hudson, & Van Rooij, 2009; Feinberg et al., 2006). Early child bearing among African American women may increase the incidences of secondary infertility more so than primary infertility (Greil, McQuillan, & Sanchez, 2016). Of the 80 million women worldwide grappling with primary and secondary infertility, only through postulating can the rates of secondary infertility in African American women be attributed to early child bearing. There are hardly any studies on the correlation between child bearing early in life and the impact of secondary infertility for African American women. The underlying factor appeared to be African American women's underutilization of medical resources to identify these causal relationships (Mathews & Hamilton, 2009). Health outcomes, quality of health care and access to care are also indicators of lower use of services (The Henry Kaisers Family Foundation, 2008). Feinberg et al. (2016) stated data on issues inherent to African American women that easily show causal relationship are captured in a controlled environment such as the military due to higher rates of utilizations and increased access. If this population does not participate in the military, then their experiences are inadvertently ignored or minimized in the research on primary as well as secondary infertility.

Healthcare behaviors are learned early in life and during adolescent years the adolescent populations are less likely to visit medical professionals because of the erroneous belief of invincibility among adolescents (Hayon, Dalby, Paddock, Combs, & Schrager, 2013). Emphasis on adolescent health care focused on reducing pregnancy and Sexually Transmitted Infections (STIs); moreover, visits to health care delivery facilities are already centered on contraception use (Hayon et al., 2013). High school students did not know of the correlation between STI's and the effect on fertility (Quach & Librach, 2008). The lack of participation in health care and lack of knowledge may carry over into adulthood leading to challenges in reproductive health that are magnified, yet underdiagnosed in adulthood (Quach & Librach, 2008). This may be a factor for African American women not using heath care services later in life because of learnt behaviors in adolescent years.

Participation in fertility options depends on parity, educational background, income, and prior knowledge of fertility options (Kim et al., 2012). In 1981, the first successful IVF occurred in the United States and it resulted in a pregnancy (Jain, 2006). This advancement in medicine led to the revolution of assisted reproductive technology, leading to its progress and rapid expansion (Jain, 2006). However, access to these services required privately funded payment and most health insurance only offered a minimal payment by limiting the number of cycles for a couple. Other insurance companies choose not to pay for the service at all. A survey of 1,500 women who sought treatment for infertility revealed that African American women sought treatment for infertility after a lengthy time in trying to conceive (Jain, 2006). The study found both Hispanic and African American women suffered from tubal factor infertility at higher rates. African American women and Hispanic women in the study had less education. Education tied to earning potential is also tied to access to health insurance (Culley et al., 2009). White and Asian counterparts earned over $200,000; while Hispanic and African American earned less than $100,000. The disparities in income also magnified the disparities in access to health insurance to cover fertility treatment leading to poor health outcomes across all domains of health (Jain, 2006). Some of these barriers continue to be the lack of appropriate information, education, racial discrimination, lack of referrals from primary care physician or other health care professionals, lack of adequate insurance coverage and cultural bias against fertility treatments leads to limited access and usage of these services (Culley et al., 2009; Jain, 2006).

Another factor affecting African American women is their low participation in clinical trials. African American women are underrepresented in clinical trials (Chatterjee, Gupta, Caputo, & Holcomb, 2016; Lai et al., 2006). As a result, it is difficult to determine successes in therapeutic interventions for this population. A study of cancer rates found the advances in cancer therapies, early detection and improvements in treatment to address different cancers have not benefited everyone (Bristow et al., 2015; DeSantis et al., 2016). This study found African American women were twice as likely to die from uterine corpus cancer and three times more likely to die from uterine corpus cancer than their White counterparts (DeSantis et al., 2016). Uterine Corpus cancer and uterine cervix cancer are also factors that can affect fertility for women. The study also found that African American women were less likely to receive treatment consistent with evidence-based guidelines. An evaluation of the SEER-Medicare database for advanced ovarian cancer showed African American women continue to face barriers that affect access to health care as well as treatment and treatment outcomes (Chatterjee et al., 2016). These barriers are not only seen in access to cancer treatment but in infertility treatments as well. There is interest and willingness among women of African descent and other minority groups to participate in clinical research. The lack of participation stemmed from not having opportunities to participate in clinical trials and a lack of encouragement from healthcare professionals to enroll (Chatterjee et al., 2016; Lai et al., 2006).

Experiences individuals have in society are also present in clinical settings (Goff et al., 2007). Health care professionals of different ethnic groups who have had negative experiences with members of a different race subconsciously and consciously engage in avoidance interactions (Burgess, Van Ryn, Dovidio, & Saha, 2007). This avoidance may surface in clinical settings, where White providers spend less time with their non-white clients, leading to poor relationships between the provider and the client thus producing poorer health outcomes (Burgess et al., 2007). Studies have shown that “racial inequalities in access to particular technologies raise critical questions about the role of racism in the medical decision making” (Gamble, 1997, p. 1776). Stereotype suppression when caring for African American women leads to unintended consequences (Burgess et al., 2007). Health care providers’ attitudes and interactions contributed to disparities in healthcare usage among minorities and this issue continues to be under explored, but is a central theme that needs exploring (van Ryn, 2002).

Increased positive interactions with individuals of different ethnic groups in clinical practice reduce the cultural bias increasing the likelihood of being referred to by their individual attributes (Burgess et al., 2007). Agency for Health Care Research and Quality in its 2012 annual report found African American women were more likely to report health care professionals as not listening to them when health questions or concerns were raised. The other challenges reported were providers not including them in decision making, not explaining diagnoses in non-medical terms, and not providing treatment options. The study also showed that the lack of having health insurance or lack of finances contributed to the lack of regular health care access and usage (Agency for Health Care Research and Quality, 2012).

Summary

Infertility has far reaching consequences for those affected. The number of definitions given to primary and secondary infertility adds to the complexity of how it is reported and documented in the research. The literature review showed the overwhelming effect infertility has on health and wellbeing on both men and women; however, infertility is often presented as a woman's issue. Equally as important are the issues of access, the ability to seek out fertility resources and use them. The financial cost to conceive can be overwhelming for families lacking the financial resources to obtain treatment. The cost of infertility treatment, the length of treatment as well as the invasiveness of the infertility treatment can contribute to psychological stressors for families. Even so, not all women experience psychological stressors. Some women have found increased marital satisfaction and stronger emotional bonds with their partners.

The literature also showed the sparse information on the ways secondary infertility affect African American women. The historical significance of race, racism and prejudice in health care services and delivery shed light on underlying factors for African American women not participating in research on secondary infertility or seeking the appropriate treatment to address the underlying causes of secondary infertility. Moreover, culturally competent services to address the stigma of secondary infertility are meager. Overall, the literature review showed there is a gap in the research. Research efforts are needed to address the existing gap and add value on the health implications for African American women diagnosed with secondary infertility.

Chapter three of this study discussed the use of qualitative research inquiry to gain insight into the experiences of African American women with secondary infertility. This inquiry also shed light on their feelings, their experiences and may aid health care professionals in addressing their medical needs. This knowledge in turn may encourage change in the responsiveness and appropriateness of treatment for those who seek out medical care for secondary infertility or for other health related concerns.

Chapter 3: Research Method

Introduction

The purpose of the study was to describe the lived experiences of African American women with secondary infertility. In it, I endeavored to give insight into the subjective understanding and experiences of these women. African American women have been largely excluded from many scientific studies of secondary infertility (Nachtigall, 2006). Many African American women do not seek treatment because they are not informed about treatment options or they lack the finances or health insurance to secure treatment (Agency for Health Care Research and Quality 2012; Feinberg et al., 2006). Lack of information limits their participation in clinical trials, perpetuating poor health outcomes for this population (Chatterjee et al., 2016; Lai et al., 2006). By documenting African American women's experiences with secondary infertility, I hope that this study will strengthen population health as well as increase health care providers' awareness in diagnosing and treating the condition. In this chapter, I discuss the research methodology and design, my role, the sample size, the data collection instrument, and validity and ethical considerations of the study.

Research Design and Rationale

I used a qualitative research design aimed to answer the research question: How do African American women describe their lived experiences with secondary infertility? Researchers use qualitative designs to explore the meaning individuals ascribe to life experiences, where themes and commonalities emerge from the shared experiences (Creswell, 2009). Small sample sizes are intrinsic to qualitative research design.

Qualitative researchers explore participants' lived experiences through in depth interviews or case studies to ascertain the meanings and themes that emerge from those experiences (Clark, 2000; Creswell, 2009; Roberts, 2013). Qualitative study questions are open ended, allowing for follow up questions from the researcher to gather more information about the participants' experiences (Clark, 2000). Phenomenological inquiry is a qualitative research method researchers use to explore first person accounts of participants' experiences with and meanings ascribed to the phenomena (Roberts, 2013; Rudestam & Newton, 2015). Phenomenological inquiry supports the argument that only those who have experienced the phenomena can truly describe it and give rise to the essence and meaning of the experience, so others can understand the phenomena (Clark, 2000). Participants' first person accounts of secondary infertility shed light on the uniqueness, similarities, and differences of their experiences to promote better health outcomes, concurrently adding a deeper understanding their experiences.

Role of the Researcher

A phenomenological inquiry uses first person accounts, ensuring that perceptions are an equitable part in the study (Clark, 2000). Therefore, as the researcher, my role was to build rapport with the study participants to relieve their distress or anxiety about participating in the study. My role included balancing the external and internal perceptions of the study participants as they relayed their experiences of the phenomena (see Moustakas, 1994). Additionally, I maintained the integrity of the study by adhering to ethical research guidelines and through recruiting only participants who met the criteria for the study. Participants who met the study criteria were allowed to review and acknowledge the study's consent form. I also informed them of the time, date, and location of interview. Furthermore, I informed participants of the techniques I would use for data collection, which included recorded interviews, transcription of the interviews, and analysis of the data to minimize bias (see Schwieter, 2011).

I reduced confounders such as assumptions, experiential understandings, and presuppositions about the express phenomena through bracketing (see Giorgi, 1985). I also used other techniques such as mindfulness and journaling. Mindfulness is intentionally being present in the moment of awareness without judgment; it requires an "affectionate attention" (Kabat-Zinn, 2012, p. 53). Journaling promotes self-regulation, learning, and reflective reasoning. Personal reflective writing promotes retention and deeper processing, and gives rise to changes in perception (Moore, Boyd, & Dooley, 2010). Throughout the study, I maintained a journal of my thoughts and feelings, which gave me greater understanding and appreciation of the experiences of these women and simultaneously helped me to keep irrational thoughts out of the study. These techniques helped me to stay on task and maintain objectivity to conclude the research.

Methodology

Phenomenological inquiry allows for the exploration of the lived experiences. Phenomenological methods involve "understanding the personal lived experience and thus exploring persons' relatedness to, or involvement in, a particular event of process" (Smith, Flowers, & Larkin, 2009, p. 40). Phenomenological study is "not interested in episteme or variable knowledge, but has its goal in uncovering of the doxa or belief patterns of human beings in their numerous meaning-making processes" (McPhail, 1995,

p. 163). Those lived experiences are significant to the individuals experiencing the phenomena; therefore, only those who have experienced the phenomena can explain it to those who have not (Todres & Holloway, 2004). There are various values, intentions, feelings, and meanings individuals ascribe to the phenomena, and these are often relayed through first person accounts (McPhail, 1995; Moustakas, 1994).

There are three overarching themes in phenomenological studies. The first is the significance of human consciousness. Human consciousness consists of imagination, remembering, perception and logical form in relaying the lived experience and brings meaning to the experience (McPhail, 1995). Second is the elimination of dualisms and the understanding that the lived experience is holistic; therefore, there is no line of demarcation between the subjective and objective world (McPhail, 1995). Finally, consciousness is temporal, reforming itself based on new experiences individuals have throughout their lives. The phenomenon can be a point in time experience or take place over a length of time, but giving a detailed account of the experience offers insights about the lived experience and its effects (Clark, 2000).

Participants

Appropriate recruitment of study participants is critical to research, while an insufficient number of participants may limit a study's efficacy (Nasser, Gardy & Balke, 2011). According to Agency for Health Care Research and Quality (2009), recruitment of study participants involves identifying the participant, adequately explaining the study, recruiting the needed sample size based on the study goals and research design, obtaining informed consent, maintaining ethical standards, and minimizing attrition rates for the participants. My study participants were African American women whom I considered to be part of a special population due to their historical exclusion from research due to individual and community barriers (see Ejiogu et al., 2011). One individual barrier impacting African American women’s participation in studies is the mistrust of researchers because of fear of exploitation; misunderstanding based on poor communication, difficulties making it to appointments, and lack of tangible benefits. The main community factor is the community’s attitudes about taking part in studies (Durant et al., 2007; Ejiogu et al., 2011; Lai et al., 2006).

To address these barriers to participation, Brown, Marshall, Bower, Wooham, and Waheed (2014) suggested equal representation of minorities in studies as well as conducting studies specific to minority populations. This study is specific to one minority group—African American women. To minimize the community and individual issues and increase participation, I chose to recruit African American women from obstetrics and gynecology (OB/GYN) clinics and churches with large African American followings. It was necessary to use more than one approach to reach the target population and obtain the appropriate sample size needed for the study because of these barriers (see Creswell, 2009).

I conducted recruitment for the study over a 9 month period, from November 2017 to July 2018. The recruitment strategies were twofold. During the first stage of recruitment, I targeted four churches and four OB/GYN clinics. I used telephonic inquiry to identify the operations managers of the OB/GYN clinics to obtain consent to recruit participants from their clientele. Likewise, I identified four local churches with the largest African American populations. Letters detailing the purpose of the study were sent to the ministers of the identified churches. Using indirect recruitment methods, I placed flyers with my telephone number and email address in some waiting rooms of the clinics and church lobbies. Flyers about the study were also placed in some church bulletins.

The second stage of recruitment involved widening the search for study participants from the OB/GYN clinics and four churches in semi-rural Maryland to other churches in urban areas of Maryland, New York City and South Florida. Recruitment also included targeting health and fertility clinics in Maryland and New York City and posting flyers in venues frequented by African Americans. Individuals shared the study information on various social media platforms including Facebook and WhatsApp.

The participants were initially selected through purposive sampling. Purposive sampling allows for concepts and theories to develop from the experiences of individuals (Devers & Frankel, 2000). According to Creswell (2009), purposeful sampling is crucial to helping the researcher identify participants with the greatest insight into the research topic. Of three types of cases involved in purposive sampling, African American women fit the category of extreme cases, that is, “those who represent unusual manifestation of the phenomenon of interest” (Devers & Frankel, 2000, p. 265).

I screened participants to ensure that they met the following inclusion criteria: (a) African American women age 18-75; (b) African American women who had previously given birth regardless of the outcome (e.g., still birth, live birth); (c) African American women presenting with secondary infertility. African American women who met the exclusion criteria were not included in the study. These criteria were: (a) African American women who do not have a uterus, (b) African American women who choose not to have a second child, and (c) African American women actively taking birth control.

All participants who expressed an interest answered the screening questions. I stored all information on the study participants in a secure folder. Study participants suited for the main study received a phone call in which I asked them about their willingness to participate in the interview. They were informed that the interviews would be conducted on a face-to-face basis in a private room at the local public library. For participants who resided far away, I conducted interviews over the phone.

Qualitative study sample sizes are influenced by theoretical and practical considerations (Robinson, 2014). The intensive and descriptive nature of phenomenological study requires a small sample of study participants. Therefore, I expected to interview a total of 20 participants. Robinson (2014) stated that cross case generalities work best with smaller sample sizes. It eliminated the potential that the researcher gets weighted down with data, therefore, giving the participants the opportunity to be uniquely identified (Robinson & Smith, 2010).

Instrumentation

A phenomenological inquiry allowed the rhetoric to be fluid and evolve based on the information participants share (Creswell, 2009). Semi-structured interview is the best method of data collection because of its versatility and flexibility (Taylor, 2005). Semi-structured format is suited to individual and group interviews offering a great deal of reciprocity between the participants and the interviewer (Galletta, 2012). Semi-structured interview is the most commonly used technique to ask questions that are relevant, experience oriented, and open ended (Geer, 1988). It is free from leading questions, affording the flexibility of asking questions consecutively allowing for additional questioning as the interview is occurring (Hood, 2016; Smith, 2007). To formulate questions for semi-structured interview, Kallio, Pietila, Johnson, & Docent (2016) proposed a semi-structured interview guide consisting of five steps. These steps are:

1. Identifying the prerequisite for using semi-structured interviews - by exploring some areas of the phenomenon.
2. Retrieving and using previous knowledge - to appraise previous information on the subject and the need for additional knowledge on a subject that already exists, but it can also add depth where there is sparse information on the topic area.
3. Formulating the preliminary semi-structured interview guide - to develop a list of specified questions to collect data. These questions can have main level questioning and follow up questions.
4. Pilot testing the interview guide - to determine if the questions are suitable for information gathering or if the questions need reformulating
5. Presenting the complete semi-structured guide - production of a finished product able to collect the data needed to add depth to the study.

The strengths of semi-structured interviews allowed for flexibility between the researcher and the participants. The researcher has the opportunity to be guided by the participants sharing their personal accounts of the phenomena (Ryan, Coughlan, & Cronin, 2009). Semi-structured interviews are an interactive experiences that are exploratory using why questions to find causal relationships (Ryan et al., 2009). King (1994) suggested these interviews are not relationship free, therefore, study participants are actively involved in the process, where probing questions are added simultaneously and questions that consistently fail to add value to the research are removed.

Pilot Study

Pilot studies aim to examine the sample size needed for the study, as well as examine the feasibility of the recruitment (Rejeski et al., 2005). According to Kim (2010), pilot studies give the researcher time to adjust and revise before proceeding with the main study. The recruitment and study protocol was conducted from November 2017 to July 2018 after securing an Institutional Review Board (IRB) approval number 10-20-17-0193621. A total of 5 participants were recruited. The recruitment strategies were two fold. The first recruitment targeted four churches and four OB/GYN clinics. Telephonic inquiry was used to identify the operations managers of the OB/GYN clinics to obtain consent to recruit participants from the clientele. Four local churches with the largest African American populations were identified in Maryland. Letters detailing the purpose of the study was sent to the ministers of the identified churches. Using indirect recruitment methods, flyers with my telephone number and email address were placed in some waiting rooms of the clinics and church lobbies. Flyers about the study were also placed in some church bulletins.

The second stage of recruitment involved widening the search for study participants from the OB/GYN clinics and four churches in semi-rural Maryland to other churches in urban areas of Maryland, New York City and South Florida. Recruitment also included targeting health and fertility clinics in Maryland and New York City and posting flyers in venues frequented by African Americans. Individuals shared the study information on various social media platforms including Facebook and WhatsApp.

The participants were initially selected through purposive sampling. Purposive sampling allows for concepts and theories to develop from the experiences of individuals (Devers & Frankel, 2000). According to Creswell (2009) purposeful sampling is crucial to helping the researcher identify participants with the greatest insight into the research question thus increasing the understanding of the problem as well as sufficiently answering the research question, thereby explaining the phenomenon. Using the same selection criteria as above, African American women fit the category of extreme cases i.e. "those who represent unusual manifestation of the phenomenon of interest" (Devers & Frankel, 2000, p. 265).

I screened participants to ensure that they met the following inclusion criteria: (a) African American women age 18-75; (b) African American women who had previously given birth regardless of the outcome (e.g., still birth, live birth); (c) African American women presenting with secondary infertility. African American women who met the exclusion criteria were not included in the study. These criteria were: (a) African American women who do not have a uterus, (b) African American women who choose not to have a second child, and (c) African American women actively taking birth control.

All participants who expressed an interest answered the screening questions. All information on the study participants was stored in a secure folder. Study participants suited for the pilot study received a phone call asking them about their willingness to participate in the interview. They were informed that the interviews would be conducted on a face-to face-basis in a private room at the Charles County public library located in Waldorf and/or La Plata, Maryland. For participants who resided far away, interviews were conducted over the phone.

Pilot studies are not intended to produce results contributing to the main study, but serve as a guide for changes that need to be made to enhance the credibility of the study (Kim, 2010; Padgett, 2008). The focus of the pilot study is on recruitment and the data collection tool. The researcher highlights successes and barriers to recruiting potential participants and makes changes to the recruitment process accordingly. The data collection tool is a semi-structured interview consisting of 18 questions with probing questions embedded in the tool. Administering the survey followed the same ethical guidelines laid out for the main study. Feedback from participants at the end of the interview must be incorporated into the interview tools for the main study to support the instrument's credibility.

Procedures for Data Collection and Analysis

Conducting research on human subjects require approval from Institutional Review Board (IRB). Terry (2015) stated IRB approval is important to maintain the integrity of the study and reduce the harm the study may cause to participants. As a result, I obtained Walden University IRB approval for study 10-20-17-0193621. No data was collected before IRB approval was given. Informed consent was explained to the participants. Each participant was informed of the purpose of the study and had an opportunity to ask clarifying questions. Participants signed indicating their consent to participate in the study. Bentz and Shapiro (1998) suggested that researchers must allow the data to emerge when conducting phenomenology study. In order for this to occur, participants gave written consent to have their interviews audio recorded. Interviews were conducted separately and on different days. Each interview was conducted one-to-one, and face-to-face or via the phone. The interview format follows an in-depth, semi-structured 60 to 120-minutes interview to gain insight, understanding, and clarify information about the phenomenon (Carey, Morgan, & Oxtoby, 1996).

At the time of the interview participants completed a demographic sheet consisting of questions asking about gender, marital status, length of time dealing with secondary infertility, number of children, medical treatment sought if any. This information was placed in secure folder to be retrieved after the completion of data collecting. The initial question presented to the study participant was a general open-ended question to allow the participants latitude to describe in detail their experiences. As the participants shared their stories, I noted voice intonation which added value to the research (Opdenakker, 2006). Note taking, according to Opdenakker, (2006) is important in three ways, namely “(1) to check if all the questions have been answered, (2) in case of malfunctioning of the tape recorder, and (3) in case of the malfunctioning of the interviewer." Additionally, I used probing questions to solicit detailed answers where information was not forthcoming. If participants struggled to share their experiences, follow up questions were asked to solicit more detailed responses. According to King,(1994) asking the right questions at the right time is important; as a result, I asked difficult and sensitive questions towards the latter part of the interview.

Data analysis began at the start of data collection and is inclusive of transcribing the interviews. During each reading, I used bracketing proposed by Parahoo (2006). Bracketing, according to Parahoo (2006), involved putting aside preconceptions, beliefs or prejudices to minimize its influence on data analysis and interpretation. Moustakas (1994) recommended grouping, reduction, elimination, and clustering in order to accomplish transcription. After the interviews were completed, I read the transcripts repeatedly with the aim of identifying key words, phrases, themes, meanings and statements that speak to the experiences of African American women with secondary infertility. Subsequent reading of the transcripts resulted in larger themes, statements and phrases broken down into smaller components. Key words, meanings, statements, and themes that emerged that did not add value to the study were set aside. As different meanings, themes, and subthemes emerge from the data notations were made. Meanings, themes, and subthemes that emerged were grouped together to meet the criteria of grouping, reduction, elimination, and clustering (Moustakas, 1994).

As meanings, themes, and subthemes emerged it served as the basis for the preliminary coding scheme. Computer Assisted Qualitative Data Analysis such as NVivo helped to facilitate an accurate and transparent data analysis process, giving a reliable and general picture of the data (Welsh, 2002). Therefore, the information from the interviews was coded using in NVivo coding (Thorne, 2000). Both the revision of the transcripts and the NVivo coding ensures the interrelatedness of the data (Welsh, 2002). Data collected was integral in answering the research question of: How do African American women described their lived experiences of secondary infertility? Therefore, helping to identify and interpret themes relating to experiences, perceptions, and understandings of African American women's experiences with secondary infertility.

Issues of Trustworthiness

Qualitative studies must have reliable and valid results (Cavanagh, 1997). Researchers argue the terms validity and reliability should not be use in qualitative research instead the term "trustworthiness" or "rigor" is more suited for qualitative research (Welsh, 2002). However, Hammersley (1990) stated that the "extent of which an account accurately represents the social phenomena to which it refers" is considered validity (p. 57). Qualitative studies allow for peer checking, audit trails, member checking and triangulation as effective strategies to promote credibility. Peer checking requires a panel of experienced colleagues to reanalyze previously analyzed data to ensure its authenticity (Rolfe, 2006). Enlisting fellow researchers to review the data and develop their own categories guards against researcher bias and promotes validity (Burnard, 1991). However, this method was not appropriate for this study as a research team was not used. Audit trails show the decision-making process in data analysis; however, this method can leave room for personal thoughts to infiltrate into the study (Guba & Lincoln, 1981).

Rolfe (2006) stated that reliability test for qualitative studies includes member checking, which involves conducting a follow up with participants after the data analysis. Participants may not recognize some of the emerging themes (Cutcliffe & McKenna, 1999). Participants who agree with themes that emerge support credibility, but for those who disagreed it was explicitly noted where the disagreement lies. Participants may also choose to not participate in member checking. Triangulation increases the accuracy of data results through use of collateral resources (Appleton, 1995). The combination of interviews, observation, documentation analysis, and reflective questions in triangulation that shows repeated themes and subthemes verifies the existence of the phenomena (Patton, 1999). Reflexivity is the process of acknowledging actions. Thoughts, feelings and assumptions about the study enabled the researchers to become aware of their influence during the study process. Reflexivity in qualitative studies establishes scientific rigor which in turn promotes credibility of the findings (Darawsheh, 2014). Therefore, I used member checking, triangulation and reflexivity to maintain credibility in this study.

Ethical Procedures

Ethical concerns were minimized in the research process because of the use of informed consent to promote autonomy, beneficence, and justice. Informed consent is an ongoing process and participants reserved the right to withdraw from the study (Bailey, 1996). I aimed to minimize deceptions in the study because deceptions reduce openness by the participants (Bailey, 1996). I did not encourage participants to become a part of the study. Participants were allowed to read the consent form, which included the purpose of the study; confidentiality for the participants; contact information if they had questions regarding the study; the participants' responsibility and rights including the right to refuse or withdraw without any discomforts to the participants and potential benefits to themselves as well as other African American women. Participants were informed that there was no compensation for participation in this study, but a small token of a $10 Chick-Fil-A gift card would be offered to each participant. The participants were informed that participation in the study required a signature denoting their willingness to participate in the study. Participants were informed that no further contact would be made after the reflective questions follow up. Information collected from the participants was stored in a secure folder.

Summary

The study is one that is qualitative, where a pilot study was conducted to determine the level of difficulty in recruitment and instrumentation testing. My role as the researcher aided in identifying participants who are largely absent from research. Recruitment of African American women came from several sources and required two a two-fold recruitment plan. Semi-structured interviews were used to ascertain information that was relevant to the experiences of African American women. A pilot study was conducted to validate the recruitment procedure and instrumentation for data collection. Ethical concerns, internal and external validity of the study were addressed and mitigated to ensure the authenticity of the study. In Chapter 4, I detailed the challenges with recruitment and the results of the study.

Chapter 4: Results

Introduction

The purpose of this study was (a) to describe the lived experiences of African American women diagnosed with secondary infertility, (b) to give insight into the subjective understanding and experiences of these women, and (c) to identify any unmet clinical needs for this population. I conducted this study with the aim of answering the following research question: How do African American women describe their lived experiences of secondary infertility? This study allowed for the identification and interpretation of themes relating to the participants’ experiences, perceptions, and understandings of secondary infertility. In this chapter, I present the themes derived from the data to answer the research question. Analysis of the data yield themes about the participants’ interactions with family, friends, and medical professionals who affect the lives of African Americana women with secondary infertility.

Pilot Study

I conducted a pilot study to determine the study’s feasibility and the usability of the survey instrument. The pilot study included five participants who identify as African American. The pilot study highlighted the difficulty in recruiting study participants. After targeting multiple sites in a semi-rural area for the pilot study and yielding few results, I found that the initial sites and location for recruitment were not ideal or appropriate for the study. , I expanded my search to large cities, targeting churches in those large cities and areas frequented by African Americans. Recruitment continued to be a challenge throughout the study. The best method for recruiting study participants was through word of mouth from individuals who had participated in a previous study or in this study. Therefore, individuals were referred through a snowball sample. Although I intended to conduct the study in a semi-rural area, challenges with recruitment led me to widen the recruitment search which resulted in a of the majority of the participants being from urban areas.

African American women who inquired about the study expressed reservations about discussing their challenges with secondary infertility. Their reservations included being uncomfortable discussing medical concerns because such challenges were viewed as private. For some participants, this level of discomfort was a barrier to participating in the study. Others expressed concerns about confidentiality, and despite being reassured that their information would be kept confidential, some potential study participants were not willing to participate. Others expressed a desire to participate in the study. However, they were not medically diagnosed as suffering from secondary infertility, even though they felt they met the study criteria. Some of the potential participants expressed the desire not to be included because it would stir up challenges for themselves and their spouses. Other study participants did not know what secondary infertility meant and required further education on the topic. Yet other participants were willing to share their stories but were not interested in participating in member checking. At the conclusion of the interviews the participants noted that they were not interested in member checking, but were delighted to share their stories as they had never been asked before about their experiences with secondary infertility. They clearly understood that sharing their stories might not provide any benefit to them, but may help other African American women in similar positions.

The difficulties I encountered with recruitment led to me changing the initial number of participants for the main study from 20 to 10. The total of number of participants for pilot study did not change, but now, only 10 participants participated in the main study. The initial number of five participants for the pilot study did not change. The five participants who participated in the pilot study were referred through snowball recruitment. Participants in both the pilot study and the main study received the same study protocol. I asked participants to sign the consent form and complete the demographic questionnaires. Participants completed the forms with relative ease and asked clarifying questions when needed. The pilot study participants expressed a common understanding and interpretation of the questions in the instrument. I asked participants for their feedback on the instrument and implementation of the questions, but they did not state any reservations with the process or the instrument. Therefore, I made no changes to the instrument and implemented the same questions in the main study.

Study Participants

The study consisted of 10 women, ranging in age from 18 to 65 years old, who were currently experiencing or had previously experienced secondary infertility. All of the study participants identified themselves as African American. Two of the participants also acknowledged that one of their birth parents belonged to another ethnic group of the African Diaspora. The marital status for the participants varied. One participant had never been married, but had been in a long-term relationship. Six participants had been married for more than 5 years. Only one of the married participants had been married just a few months. Additionally, one participant reported being divorced.

The educational level for study participants also varied, with one participant having a high school diploma and another having a Certified Nursing Assistance license. The remaining participants had obtained tertiary degrees: three had undergraduate degrees in various subjects, three had associate's degrees in nursing, and two had master's degrees in social work. The study participants hailed from different professional backgrounds with three of the participants employed as registered nurses. Two worked as case managers in child welfare, one worked as a certified nursing assistant, one as a pharmacist, one as a supervisor, one as an administrative assistant, and one as a teacher. The participants came from different parts of the United States, including eight participants from Florida, one from Maryland, and one from New York.

The participants experienced secondary infertility from 1 to 11 years in length. Some participants did not know the cause of their infertility, whereas others attributed their secondary infertility to a number of medical factors: one study participant indicated low prolactin levels, one participant reported an incompetent cervix, one participant cited polycystic ovarian syndrome, two participants reported maternal age as well as their spouse's reproductive health challenges, and five participants reported multiple miscarriages. Three of the study participants reported that they had struggled with primary infertility prior to experiencing secondary infertility. Three of the 10 participants had at least two children whose ages ranged from 14 to 38 years. Five participants had single births, one participant had a set of twins, one participant had a still birth and the other participant's baby died shortly after being born. Only eight of the study participants wanted more children; the other two participants decided, along with their spouses, that they would be content with one child.

Data Analysis

The data I analyzed consisted of the participants' verbatim responses. I have identified the participants using pseudonyms to protect their privacy. Four major themes emerged from the interviews with the 10 study participants: (a) defining family and adjusting to the change in definition of a family, (b) experiences with secondary infertility, (c) psychosocial stressors and supports from friends and family, and (d) treatment and intervention for secondary infertility. In the following discussion of themes, I show how each theme and subtheme intersected and diverged to highlight the experiences of African American women with secondary infertility.

Theme 1: Defining Family and Adjusting to the Change in Definition of a Family

During the interviews, I asked the participants to define family and speak about what having children meant to them. Each of the participants spoke with passion about their vision of a family and how it has changed over the years. Secondary infertility has robbed the participants of their expressed desires, compelling them to change the way they defined family and its development. Many of the participants expressed strong feelings about the loss of control in orchestrating their own family, but each participant expressed appreciation for the opportunity to have other children to share their love with over the years. The subthemes for Theme 1 are (a) defining family, (b) marital relationships, (c) joys of motherhood, (d) legacy of having children, (e) adoption, (f) changes in interaction with birth child, and (g) information shared about secondary infertility with the child.

Defining family.

Many of the study participants defined family in the traditional sense of having a father and mother in the home. Many of the family descriptors had typical gender roles, where the woman's role involved caring for the children and maintaining the home. Some of the participants even cited their upbringing as a model for their future family. Other participants discussed the importance of having an extended family around to help in raising the children.

India subscribed to the African proverb, "It takes a village to raise a child." India's vision of a family included not just her immediate household of her husband and son, but also, "Being around my siblings, having a child, showing affection and everyone caring for the child." India comes from a large family of seven siblings. She sees her siblings as integral partners in her son's upbringing. She allows her son to spend quality time with them because she wants him to understand the importance of family. She relies exclusively on her family to provide childcare because this is where he learns the oral history and practices of their family.

Samantha expressed her desire for her extended family to be a part of her children's lives. Her vision of a family was not different from the vision expressed by many of the other women, but she made clear to her extended family her desire that they become active participants in her children's lives. She stated,

> The complete family unit consists of a husband, wife, having children, and having extended family of aunts, uncles and grandparents. Because of my upbringing, that was the vision I had for my family. The extended family was very involved and shared my vision on how a family should be regarding the upbringing of the boys.

Jane’s responses concurred with Samantha’s response as she spoke of the importance of having extended family around her. Jane described her definition of a family through her former husband’s desires. Her former husband is from a large family and he grew up in a large household. She reported that he grew up among many siblings, which was crucial to his self-esteem and identity. She explained,

> He is from a very big home, where his father was married to 8 wives, and he had many siblings. He grew up among 18 sisters and 10 brothers. So he grew up in a large home, so having six or seven kids made him feel like a man.

Karissa’s took an intellectual approach in her definition of a family as she philosophized about marriage for African American women and the cost of child rearing for her and her family. Karissa offered her explanation on how she viewed family, stating,

> As a child growing up, I envisioned a family that consisted of 4 children, being a stay at home mother like my mother was, and having a wonderful husband. This was the model of what a family looked like to me and what I envisioned for myself. After being exposed to the reality of black women having a hard time finding a spouse as well as learning that college was the key to economic success,

> my vision changed. I became more reserved in the number of children that I wanted. That number changed to from four to two children. So I pursued a college degree, and then got married and then reality set in.

Andell was passionate about what family meant to her. She spoke in reverential terms about her father and how he influenced her and her upbringing. She explained her thoughts about family, noting,

> Having a family is security and comfort; especially since I am married having children will just complete my family life. As a black woman, it is important to have someone to follow in your footsteps, or having someone down the line to care for you, and someone to care about. Having someone to love is important because having children means a lot. Growing up my family life was happy. We got along well. We had comfort. We shared and had a great understanding of each other. Our father was the breadwinner, he cared for us, he taught us, and he did everything for us. My family life as a child was complete and that is what I am now looking for that I don't have.

Edith, however, did not define family in those terms; she did not give much thought to having a family. For Edith family was an afterthought. She stated her views candidly on family and her perception,

> In all honesty, I had not thought about it. I even told my husband that I had never given much thought to defining a family . . . you know how some people say they want three children and a white picket fence. I had never thought in that manner, you know, my thought was whatever happens, happens. I did not have any

> expectations of wanting two or three children or a certain type of house or so on and so forth.

As seen in the participants' accounts, family played a significant role in their early lives and their perceptions of what their future family should look like. The participants also showed the degree to which changes in the definition of family has affected how they see their own families. The way they defined family was interwoven in how they fostered their marital relationships, but many participants found support in their marriages to help them redefine what family should be.

Marital Relationships

Another subtheme of Theme 1 was martial relationships or long-term relationship and secondary infertility effects on these relationships. Not all the women in the study were married, or in long-term relationships, one participant was divorce. Her experiences differed from those who had been in longstanding relationships. For those in marriages and committed relationships, speaking about the effect secondary infertility had on the marital relationships was important. Marital relationships for some women served as a buffer as they dealt with the challenges of secondary infertility. Simone reported that her family did not pressure her because she only had one child; as a result, her experience was not as stressful. Simone highlighted her experience as,

> The concern for having children was centered on what we did in our home, and just this house. Since the burden fell more on him than on me at the time. We just focused on what we're going to do as a couple and when he made that statement

> that this child is perfect, those were his exact words, we don't need any more children, I said ok.

Simone also spoke about the fact that she did not experience marital discord because of her inability to have another child. Simone stated that marital discord was not a part of their family's story because they mutually came to the decision to not pursue having additional children. She said, "Later on I think about 7 or 8 years later, we decided we are not going to stress or put ourselves through this we are not going to try anymore." The family settled on not trying to have any more children and made a conscious decision to just enjoy each other's company.

Andell discussed the fact that her marriage helped her to cope with not being able to conceive or successfully carry a child to term or have a live birth. Andell stated, "My husband already had children who were young adults and so that may have been a factor in our relationship not facing discord due the failed pregnancies."

Samantha stated that her husband was supportive, and he was open to whatever decision she made regarding her pursuit of having a child. Lori acknowledged that her husband was supportive too and would often tell her that "It was in God's timing that she would have a child." Both Samantha and Lori acknowledged that their marriages served as strong buffers for them during their times of disappointment. Marian who was unmarried, but in long standing relationship, found that it was her desire to give her husband a child that served as a source of stress not the relationship itself.

For other study participants, secondary infertility led to marital discord. For Karissa the marital discord was great and placed her on the brink of a divorce. Karissa stated that her experience was one that affected her and those around her. She said,

> It put a strain on my relationship with my husband, as he would have to take time off to take me to appointments, where I only became more disappointed and devastated after each visit. It started affecting his earning potential and I was depleting our savings. I did not want to be intimate with him, because I could not enjoy our intimacy. Moreover, we argued repeatedly. One day he cupped my faced and lovingly asked if I wanted a divorce. I looked at him puzzled and with tears in his eyes he expressed how much my quest to become pregnant was impacting him too.

For Jane the result was not so favorable, she had successfully carried a child to term who was now a young adult from a previous relationship, but after several years of marriage, her husband initiated divorce proceedings because she could not carry another child to term. For her ex-husband and his culture, these were acceptable grounds for a marriage to be dissolved, but in the USA, it was described as irreconcilable differences. Jane recalled the reactions from her husband each month and it how it affected their relationship long term. Jane stated,

> Every month meant so much to me. There would be signs that indicated that I was pregnant, but then two days later my period would appear. I was so unhappy and sad. Every month when I had my period, my ex-husband would exclaim, “Oh my God! Again?! Again?! What happen, I thought we were through with this?

> We have to go through this again?" As soon as I heard that from him I would just feel down. I would not eat. I just felt so down. It was like I had done something, like I just killed somebody with that "Again" expression. It made me feel so unhappy. I felt a void, an emptiness, as each month goes by and another I just felt so empty. It was worst for me at the end of the year because I was going into another year without having a child.

The accounts above explored the support as well as the challenges that arose in marital relationships because of secondary infertility. Some of the participants were able to find support in their marriages and deal with the inability to conceive. Others lost those relationships or were on the verge of losing relationships because of secondary infertility. Some endured harsh criticism because of their inability to carry a child to term. This further affected their self-esteem and the ability to care for themselves and the family as a whole.

The Joys of Motherhood

The third subtheme emerging from the data was the Joys of Motherhood. Four of the study participants were elated when discussing the uncontainable joy motherhood had given them. Samantha was the most descriptive as she detailed her feelings about having her twin boys. Samantha reported,

> It was the happiest time in my entire life – you know getting pregnant, having my kids and being a mother. It has affected me in my adulthood and my emptiness because my two boys are not home. I don't want to say there is no more joy in my life, but raising them was the joy of my life. My husband was the best father

> in the world. I sometimes joke that my husband wanted his children more than he wanted me. He was a very happy man with his children. I know that my greatest strength was being a mother.

Marian also highlighted the joys of motherhood. Marian gleefully stated, "Having children brings me joy, I always wanted seven children, and I wanted to have a big family. For me, there is no greater accomplishment than being a mother." Simone, on the other hand, spoke about being a mother in relation to others. She states, "I did not want to be a 40 year old mother sitting in a doctor's office with a bunch of 20 year olds, but even so, I would not trade my experience of having my child; being a mother has been a source of joy for me, my immediate and extended family."

Lori also expressed similar sentiments. She added,

> It is a blessing! As a woman it is one of the most important accomplishments in life. I have been blessed with two children and they are the highlight of my life, they are the reason that I live. Being a mother means the world to me, seeing their happiness and sadness. It is a most wonderful experience every woman should have the pleasure and joy of experiencing.

Some participants found joy in being a mother and their identity was uniquely tied to that role. Some of the other women found being a mother to be a great accomplishment. With this great accomplishment comes the joy that extends to having a legacy in their children; as a result, the next section explored the legacy of having children and the variation across experiences.

Legacy of having Children

The subtheme of legacy of having children emerged repeatedly in the interviews. Many of the study participants talked about having children as an opportunity to carry on the family name as well as carry on family traditions. Having children for many served as a form of validation of their womanhood and reduced the societal pressure to not be one of those women who failed to have a child. Samantha explained, “It was the best thing to ever happen to me as a woman and I wish for every woman to experience motherhood, although I know for some it is not a reality.”

Janel and Marian highlighted their delight in raising someone who was similar to them, as the most wonderful gift to given to anyone, especially to their husbands because they see the children’s temperament and attitudes that are very similar to their own. Lori agreed with the views expressed by the other women, but she also pointed out the challenges of adhering to society’s social construct that there is a correlation between womanhood and motherhood and by extension having a legacy through children. She stated,

> Having a child is a blessing and as a woman, that is one of the most important thing you could accomplish; because in our society you are regarded as less of a human being for not having a child. You are considered selfish. So much value is placed on children, but there are often other factors that contribute to why women cannot have children.

Karissa and Jane shared similar views of passing on traditions, customs and practices through having children, notwithstanding the fact that secondary infertility would impede their ability to do so. Karissa described having children as,

> It is about having your legacy passed on from one generation to the next. It is about sharing your genetic information with your child and seeing their temperaments and attitudes that mimic yours. For my spouse having children is important because everyone in his family has children and so for him it was only natural his legacy would include children.

Jane highlighted how her former husband's culture intertwined uniquely with hers, therefore, placing a strong emphasis on having children. She described her experience with the cultural emersion and its effects on having children by stating,

> My former husband is from a culture that places emphasis on having a child, because they believe any woman without a child is different from other women. Having children actually meant so much to him, not having just one, but having many. He hoped to have both boys and girls, so that the home would be full of joy and laughter that kids bring to the home. Children fulfill every aspect of life, having someone who we can share time together. We can be happy together. We can live together as long as we are alive; and when I am older and no longer able to care for myself, I can look up to my children to care for me. So having children means a lot, it is fulfilling our life long experience of not being alone.

Many of the participants' views aligned with Jane that the tradition of being cared for as they age is unique to their experiences and caring for family is passed from one generation to the next. Secondary infertility has affected that experience for some of them, even now as they serve as caregivers for their aging parents. There is a level of concern as to who will care for them when they are older if they have no children to step into the role of caregiver as they age.

Secondary infertility has affected the legacy of having children in a different way for other participants. Andell is one such participant; she described how her ability to benefit from the legacy of having children was thwarted by secondary infertility. She stated with consternation,

> I am looking to leave a legacy behind; your children are your legacy. I don’t have that to look forward to. My nieces and nephews may help me to feel a little bit of comfort but I am not complete because they are not my children. It is very encouraging when you have your own children you are able to train them and raise them in the same way you were taught, but I am unable to teach them because I don’t have children.

The inability to leave a legacy behind was emotional for Andell. It is, indeed, important for individuals who have subscribed to the role of being a mother to feel fulfillment that comes through having children. When this is not achieved, an emptiness that cannot be filled exists for the participants. This section explored how the legacy of having children affected the study participants. The following section explored how other families tried to be creative in developing their legacy through adoption.

Adoption

Some of the study participants, who learned of their fate of not having additional children, explored the possibility of adoption. Adoption would allow these families to give legal status to children in the foster care system, but they would miss out on the ability to give birth to the children being adopted. Jane stated that she is actively pursuing adoption through the foster care system, and has successfully completed the PRIDE training for the state of Maryland and is awaiting a home study. She recognized the importance of opening her heart and her home to children who need a permanent home. Jane stated,

> I have now begun to have a change of heart; you can now have a family that is not associated with you by blood or whatever. I have now come to appreciate that people can live and take care of children that are not your own – through foster care/adoption – and live well and live happily as if they are your own.

Samantha explored adoption because her friends who suffered from infertility had been successful in the process. Samantha recounted discussing the option with her husband and they had begun researching about becoming adoptive parents. She stated,

> Initially the cost served as a deterrent, but as I did further research I was turned off by the fact that an acquaintance who had adopted was murdered by the adopted child. Both my husband and I chose to walk away from that option to avoid the same fate.

One study participant briefly highlighted stories of witnessing others going through adoption to complete their family. One such study participant was Edith. She recounted,

> My friend who had struggled for many years to conceive chose to adopt because her age was becoming a barrier to conceiving. I was not interested in adopting, but was a source of support for my friend who also struggled with infertility.

Some of the other women expressed aversion to adopting, because it was not the same as having their own children. They openly acknowledged there are children in need of adoption, but having their own children offered greater solace. Karissa stated,

> Even though it seemed selfish, I would never want to adopt. I have little to no information on what challenges the children might have and how to handle them. At least, if I had my own I already know that child's history.

This section explored the desires among some of the participants to use adoption to fill the void left in their hearts and homes because of secondary infertility. A number of the participants were open to the possibility of adopting, and were influenced both positively and negatively by the experiences of others. Other participants did not give any thought to adopting because it was not the way they saw their families developing.

Changes in Interaction with the Birth Children

The subtheme of changes in interaction with birth children emerged from the interviews as the participants discussed their lives and the importance they placed on having children in their homes. Some of the participants were willing to allow their children to develop and explored the world; others were less inclined to do so because of fear of dealing with multiple losses. Edith and Lori showed more willingness to let their children explore the world and develop according to the children's own philosophical view of life. Edith reported,

> I was always under the belief, which is true, that is you don't treasure a child, because the child is really a gift from God. God has given you this child as a blessing. It is His child to raise and care for and that's how I've always looked at it. She is not someone that I value and treasure or held on to. In fact, when it was time for her to go to college, a few of my friends said, "are you going to let your only child go away?" and I said, "She has to go to grow." With that being said, we sent her on her way and she spread her wings. In fact, once she graduated from college, she was able to obtain an internship in New York City, and now, she lives in New York City. My child is now 24, she is a young adult, she has to live her life and we raised her to be independent.

Similarly, Lori showed more openness in letting her children explore the world. She emphasized that letting her children go does not mean she does not love them, it just means that she understands the limitations of her role as a mother. Lori stated,

> I am the opposite, I love my kids and we are very close, but we also believe that everybody has to find their path and grow. My son is in the Airforce. He went to college, while I was overseas. My daughter is in high school, so we have always allowed them to grow and be independent kids.

Janel discussed the ideal balance for her as a mother. She has maintained that the role of a mother includes nurturing and protecting, but she understands her unique role in ensuring her son experiences the positive and negative consequences of his choices. Janel said,

> I am overprotective as a mom. I don't want anything to happen to him, but not that overprotective, where I lock my child in and don't allow him to do certain things. I have my son in many activities because I like to see the joy when he is winning, and be there when he is not winning. So I think I am being overprotective because I want to keep him safe, but not to the point where he does not enjoy life, because that is why we are here, to enjoy life.

For other women like Samantha, it was quite difficult to accept that her children were growing up and would leave the nest. Samantha spoke about her love for her children and how it affected her interaction with them. Samantha said,

> I went into over-love; I think. I did in actuality. People who know me will say to you "she talks about the boys; there is no one like the boys, the boys, the boys." Sometimes I feel like I loved them more than anyone else and I also told them that. I told them that no one would love them as much as I love them. There was so much joy in being a mom with them. I always tell people not to rush for your children to grow up because you have such a short time with them.

Similarly, India expressed how her interaction with her child elicited more affection from her. India attributes this in part to her son being autistic and her wanting the best for him. She said, "Well, having my child makes me learn to appreciate life more. I hug him; I try to do everything I can for him. A day doesn't go by where I don't squeeze him and hold him close to me because he is all I have."

Jane on the other hand, is more actively involved in her adult son's life. Jane's life experience served as impetus for encouraging life choices for her son. She does not want him to suffer the same fate she did. Jane stated, “I think my interaction changed with my son, after learning that I had secondary infertility. Now I talk to him about finding a wife soon and not waiting too long, because I know that age might also be a factor when trying to conceive.”

Simone recalled the way she raised her child as not deviating from the way she had initially planned to raise him. She explained,

> I let my son developed as he normally would have. I did not think that I hover. Perhaps, I think I should have hovered more, but I was not the hovering kind. Helicopter mom, is that what they call it? No, I was not a helicopter mom. In my parents’ house it was that adage children should be seen and not heard. I try to not have that. I try to give him a chance to express himself. I try to not hover.

This subtheme of changes in interaction with the birth child highlighted how the participants interacted with their children after the challenge of secondary infertility. Many of the participants shared similar characteristics in trying to protect their children and hold on to them in order to not experience multiple losses. Others showed more resilience in allowing their children to explore the world with the confidence that they had given them the tools to succeed. The next section explored the information shared with the child about secondary infertility and how it affected the participants’ ability to have additional children.

Information Shared about Secondary Infertility with the Birth Child

Discussing secondary infertility with others was painful for many participants. The participants felt that many people could not understand the challenges they were facing, but even more challenging was the difficulty in explaining to their children that they would not have brothers or sisters due to secondary infertility. Some participants were very upfront with their children about the reasons for not having any more children. For instance Simone stated, “We told our son just like his father said, you were the perfect child and we did not need any more children.” Marian too stated that she explained to her daughter about the reasons for not having any more children. She reported, “When my daughter asked about siblings, I told my daughter that is was hard to get pregnant again, but it will happen when the time is right. God will take care of it.”

Samantha too, was very open with her children about her miscarriages and the fact that her age was a barrier for her having additional children: She added, “I told my kids, mom had a pregnancy and lost it and they knew that mommy wanted more kids and could not have any more. They understood that I was getting older and of course I discuss that with them.”

Jane discussed how her son began championing fertility treatment for her after she told him about her inability to have additional children. She explained,

> It wasn’t easy for me to explain to him, but I had to let him know what was happening. I told him the challenge I was having, and he said as long as you are ok, you could keep trying to have more kids. Then he would come home and tell me about people who did IVF. He would say “look at what they did, look at their age, mom.” He was going back and forth, reading information about infertility treatment and trying to explain it to me. I know he was trying to tell me there was nothing wrong with me.

Edith learned she had to quickly explain to her child what was happening and why there were no additional children in the home. According to Edith, she felt pressured to have additional children through her daughter's actions. She explained,

> Oh Yes! We definitely did share that information with our child. I guess at about five years old, she started asking about brothers and sisters. And then at one point prior to her teenage years, she brought home pamphlets about adoption. She actually did this a couple of times. We can't exactly recall how we handled it, but I felt a lot of pressure with her bringing those brochures home.

Other participants were apprehensive in sharing information with their children about their struggle to have additional children. Janel stated that she did not share any information with her child about secondary infertility. She pivoted to things that would make him think twice. She noted,

> I told my son brothers and sisters don't come as easy as making pancakes. There is more to it and when it comes, it comes, you are the only child and you are spoilt with a lot of things. Having a brother and sister will include sharing those things. I did not go into much detail because at the end of the day you want to keep a child in a child's place.

The age of the child was also a deciding factor in whether or not information should be shared about secondary infertility and the limitations of having more children. Lori and India agreed that their children were too young to have those discussions with and they felt it was a burden to discuss with them. According to Lori,

> We never did. We felt he was too young. He was in school and we wanted him to be a kid and not worry about that. My son was too young, so I did not share with him what was going on. He just knew mom was in the hospital when I had the miscarriage. My child is very weird, he was happy being an only child.

Conversely, India is already rehearsing how she plans to brooch the subject with her son. She is not discussing it now, but hopes he will understand as he gets older. She stated,

> Since he is so young, and I really don't want to bother him with this. I remember one day he asked if he could get a sister or a brother. I said I am not sure. I try to not make him think that he would not have a sibling, but I know one day I will have to tell him why he is alone and does not have any siblings.

The previous themes and subthemes showed ways that secondary infertility influenced family development for the participants. Other participants have chosen to explore other possibilities like adoption to complete their families, while others have out rightly rejected adoption as an option for them. Integral to the development of a family is the handling of normal day-to-day questions such as asking for a sibling. As previously stated, the participants have a unique understanding of their children and how much information, if any, should be shared with them about them not having siblings. The participants highlighted how discussing this question compelled them either to disclose or not disclose to their children about their struggles with secondary infertility. Many chose to share their experiences, while others were conservative in their approach. Through it all the participants made the decision that was best for their children as to whether the child should be aware of the implications of secondary infertility. Discussing secondary infertility can be as challenging for adults as it is for children and it is not always easy to find the right words to explain it, especially if the individual experiencing secondary infertility has not accepted the reality of their loss.

Theme 2: Experiences with Secondary Infertility

This study was conducted with the purpose of exploring the participants' experiences with secondary infertility. For African American women these experiences are not acknowledged or discussed openly. It took great strength on the part of the participants to talk about these experiences. Discussing these experiences exposed the vulnerabilities often hidden from public view in the lives of African American women. The subthemes that emerge from the interviews are (a) defining secondary infertility, (b) experiences with secondary infertility, (c) miscarriages, and (d) male partners' influence on conception.

Defining Secondary Infertility

Many of the participants struggled with defining secondary infertility. About half of the study participants knew that secondary infertility affected their ability to have a second child, but could not quite define it. Marian did not define secondary infertility. Janel defined secondary infertility as "not being able to have another child." Samantha defined secondary infertility in relation to primary infertility. Samantha stated, "It was more primary infertility, but secondary infertility also happened, but never led to fruition. It was after eleven years of trying that I was able to conceive."

Edith did not think that secondary infertility applied to her, even though she was encouraged by her coworkers who saw the flyer to participate. It was after asking clarifying questions, she recognized that she suffered from secondary infertility. She stated,

> Actually this is was the first time I am hearing of secondary infertility. Secondary means not first, after the first child thereafter would be secondary. That is what it means to me.

She was not the only one who was not familiar with secondary infertility even though they experienced secondary infertility directly. Simone said, "I never heard those words before until I heard about the study, even though I knew I struggled to have more children." Other women saw secondary infertility as limiting their abilities to dream for the future. For example, India said,

> Secondary infertility means shattered dreams. Here comes the inability to have any more children. There is no dream of seeing kids playing together or my kids playing together or watching them play with their toys, talking to each other, giving jokes or even taking to them to the park to play.

Embedded in India's response is deep sense of hurt and double loss. Both India and Lori expressed intense hurt. When Lori was asked about secondary infertility, she sadly whispered "it was painful."

Karissa was more candid in the way she defined secondary infertility. She stated,

> Secondary infertility initially meant nothing to me. I did not know about it and was not concerned with fertility issues. Recently, it has become a reality that I

> cannot escape. So now it means loss - loss of what I cannot accomplish by having more children. Just saying those words brings sadness to my heart. I don't think I have managed the challenge of secondary infertility. I think I just gave up and lost hope.

Jane's definition of with secondary infertility was in relation to how she was perceived by those around her. Jane explained,

> Secondary infertility means being unable to have another child. At first, I did not think that applied to me because I could have children it was just that I never brought them to term. I never felt like I was one of those women who could not have children. It is only now that I fully understand that I too, struggle with secondary infertility and I have to face the reality that I cannot bring forth life and I am perceived differently by other women.

For Andell, the pain was intense, she did not have a clear definition of secondary infertility, and she did not know what the underlying causes were for her not being able to carry a child to term. She explained,

> They did not give me a real reason as to what caused it. When you are at the six month mark, going on the seventh month, and you have a miscarriage, it is just so… they did not give a perfect explanation, because they don't know my body.

Defining secondary infertility was difficult for some of the study participants. They had all experienced secondary infertility, did not know what it was called, or just accepted their fate as being able to only have one child. Some participants just knew that it was a painful experience resulting in one or multiple miscarriages. Along with the difficulties in defining secondary infertility, is the challenge of talking about the experiences with secondary infertility.

Experiences with Secondary Infertility

Acknowledging secondary infertility was difficult since many of the participants had previously conceived regardless of the outcome. Some participants impatiently waited to have more children after the first child; others had begun actively taking birth control pills; while others just hoped they would conceive because they were engaging in sexual activity without the use of contraception. For instance, Edith was not ready to have a second child and she was content with not having any more children immediately. Edith described her experience as,

> After giving birth to my daughter, we decided to wait a few years. I initially began taking contraceptives again, and then we stopped a few years later. I was trying, but it did not happen. I never did go to see a specialist for that reason, because as I stated, I did not have an idea of wanting two or three children. So I let it go. I did not dwell on it.

Secondary infertility only became a reality for other participants when they have actively tried conceiving or because of other medical procedures that indirectly revealed a diagnosis or a condition directly linked to the inability to conceive. Karissa shared the moment she learned that a medical condition common in many women had led to her being diagnosed with secondary infertility. Karissa added,

> I married my husband in a small wedding surrounded by family and friends. I remember it like it was yesterday. The wedding coordinator congratulated us and

> said, “Let me know when to plan the baby shower.” It was all in jest and we all laughed about it. Shortly thereafter, I found out I was pregnant with our first child. I was 25 years old and it was an exciting time. All my siblings had already conceived and had their families. It was only natural that I did the same. After getting into a car accident, I lost our son. As time went on, I noticed that we had not conceived as easily as I did at 25. I was now 28 and spoke to my OB/GYN and Primary Care Physician. They both advised me to relax and that it would happen, since I had not experienced any challenges in having my first child. I was not sent for any testing and so I assumed they were right. By the time I was 30 years old, I became overly anxious about not having a second child. I went to see a specialist in Philadelphia. At first glance, she told me that everything appeared fine, but as she conducted a closer assessment she determined that I had polycystic ovarian syndrome (PCOS). I was devastated because I had never heard of this disorder before, and symptoms I had were attributed to other health concerns. I was in denial. I told her about the car accident, subsequent tests revealed no reproductive system injury. I spent a large amount of time and money going from specialist to specialist. I tried a nutritionist to change my diet and started walking to reduce the weight I had gained.

Other participants, who wanted large families, after learning of a diagnosis of secondary infertility, shattered that reality of a large family. Based on her experience India recalled how she had envisioned her life. According to India,

> It is like a nightmare. I watched other people with their kids and get envious. It is a part of life that I will have to deal with. Gradually, I am trying to embrace it, but it is not easy. It came as a surprise, I was in awe, and I felt very empty. I was asking why me? Why it had to be me? It took me a while to accept, I still have not accepted it fully.

Simone on the other hand, spoke candidly about the process that she went through to figure out why they were unable to conceive at the time. She claimed,

> Well, when we started to investigate why we had not conceived, the doctor said something to me about a tilted uterus. I had never heard that before. He said that was the problem. He also did a test, an HSG, to see if my tubes were blocked.

Marian pointed out that she wanted a large family, but did not know initially what the underlying causes were that prevented her from being pregnant. She later understood that once she conceived, she would need medical help in order to carry the baby to term. Marian explained,

> When we decided to have kids, we tried for about two years and nothing happened. When we decided not to try, then we got pregnant. It was stressful. I talked to a gynecologist about not conceiving and he gave me a six month waiting period, he said if I did not conceive he would start to do some tests. I got pregnant within the time frame and had to have cerclage done. I was diagnosed with incompetent cervix.

Samantha, Lori and Andell's experiences with secondary infertility were directly connected to primary infertility as they had suffered miscarriages prior to the birth to their other children. Lori stated, “It was a very trying time, after a while it got painful and discouraging.” Samantha recalled her experience as one that is interwoven with family conflict as well trying to start her own family. She recalled,

> I got married at 25 and at that time I was pursuing my academics, but after two to three years of not using contraceptives, I never got pregnant and I was sexually active. Since I had no children I took care of my sisters’ children to the point where their husbands had big issues with me caring for my sisters’ kids. The doctor never did a test on my prolactin levels. I was reading an article on prolactin levels. I was seeing a fertility doctor and I asked him to check my prolactin levels because I was reading about it. And lo and behold that was it, and they never thought of testing my prolactin levels. Once I was treated, I got pregnant with the twins. I remember when I was struggling with infertility, I saw a lady with a set of twins and I turned to my husband and said, “how can she manage two children, God bless her.” When we went to the doctor to do our test, he told us we were also having twins, I exclaimed what a blessing!

Andell spoke about her experience and how it affected her. Her experiences with primary infertility were directly connected to her struggles with secondary infertility. She explained,

> The doctors don’t know my body in this form to define what led to the infertility. I did all the tests. I questioned myself why can’t I hold the baby then? I don’t know? So it makes it more difficult. At first, they thought I had a blocked tube and they sent me to a do a test to clear my tubes. I am not sure if my tubes were

> blocked because the dye that the doctor injected, went through and so right after that I got pregnant. Five to six months later I had a miscarriage. I don't know if it was hard work. The doctor stated that he does not know what caused the miscarriage because I was so far ahead. Even after I lost the baby I went back to do the test to see if my tubes were blocked. I did the test here and, in another country, and they were not blocked.

As the participants tried to explain their challenges with secondary infertility, some of the participants had no formal diagnosis or they learnt about the condition through happenstance. Some of the participants did not know what to make of the new information they had received; some accepted it while others questioned why it happened to them. Some of the participants truly believed that they were the cause of their families not growing, but other participants experience secondary infertility indirectly because of their partners.   The next section explored how male infertility affected conception for some of the study participants.

Male Partners' Influence on Conception

Male infertility contributed to some participants experiencing secondary infertility. The male role in fertility treatment is sometimes passive, therefore, seeking treatment and making medical decisions about infertility becomes the responsibility of the woman. Some participants did not know if their partners contributed to the couple's secondary infertility, but other participants understood the role their spouses played in the couple's infertility. In fact, Edith who had struggled to have a second child stated that it was by chance that they learnt of the role her husband played in contributing to the fertility challenges for the family. Edith discussed very candidly how that came about for her family. She said,

> We decided that we are not going to stress or put ourselves through this. We are not going to try anymore. So my husband actually had a vasectomy. In doing so, it was determined that he only had one vas deferens. So that was part of the issue, which we were not aware of the time.

Similarly, Simone's husband was hesitant to do testing, only after learning that she had been healthy and was not the cause of the family's infertility struggle, was he willing to get tested. His wife was healthy, so he consented to have the test done. Simone reported,

> I passed the fertility test and so we started to look to my husband. When we tested him, we learned that he had a low sperm count. He was initially reluctant because it involved him taking injections repeatedly. Finally after a while, he agreed to do it and he did one or two injections and after the second set of injections he said, "I am not doing this anymore." During that time I got pregnant. Later I found out that I had fibroids that may have contributed to the problems.

Some of the spouses were supportive during the testing procedures and volunteered to be tested alongside their partners. Karissa stated,

> My husband was very willing to get tested and he went through each test. The nurse called with the results and told him all his "soldiers were marching," it

> triggered an angry response in me, because it only confirmed that I was the problem.

Samantha also highlighted her husband's supportive role. She said, "It took 11 years for me to conceive. Both my husband and I went through all the testing. Surprisingly, my husband went through the entire testing just to be sure he was not the issue. He was willing to do all of that."

Jane reported that she did fertility testing in both New Jersey and in Maryland and both times she had to do so on her own. Her husband was not present at any of the appointments because he believed that he was fertile, and she was the problem.

Andell reported that her spouse was not interested in getting tested because he was confident in his abilities to impregnate her. Andell stated,

> After a few years, we went back, and they asked my husband to test his sperm count, but he refused. They wanted him to do a sperm test; he refused because he stated that he knew he could get me pregnant. They wanted to find out if his sperm count was low or what was going on, because they said after a certain time, when you are getting older the sperm is not strong enough to reach the egg. We were already much older by this time. But it just never happened again.

For those participants whose partners struggled with infertility, they were willing to work through the medical procedures to ensure that they could start a family. Many of the other participants highlighted the willingness of their spouse to participate in fertility procedures. Only one spouse already had grown children from a previous relationship and so he was less inclined to participate in fertility treatment testing. Although the desire to have children existed for Andell, the resistance she encountered from her partner to seek fertility treatment is not uncommon. Men who have fathered children are less inclined to seek fertility treatment, notwithstanding the fact that fertility can be affected by a number of factors that can only be discerned through appropriate testing. In the next section, the participants detailed their experiences with miscarriages on their journey in dealing with of secondary infertility.

Miscarriages

The subtheme of miscarriage surfaced repeatedly during the interviews. A small number of the participants in the study suffered from miscarriages stemming from many factors. Unfortunately, some of the participants did not know what led to their miscarriages. Other participants were given limited information and were treated as less than during their experiences with medical providers. Marian detailed her experience of miscarriage and how she dealt with having a second child soon thereafter. Marian said:

> At nineteen weeks, I had a miscarriage, he lived for two and half hours and then he passed away. My doctor recommended that I could try again after I have a normal cycle. I started trying after it returned, and I got pregnant six weeks to the date after I had the miscarriage. At 32 weeks, I went into premature labor. She weighed four pounds five ounces. I did not have another one until she was 13 years old. Five years later, I was pregnant again and I had another miscarriage at nine weeks.

Similarly, Lori talked about the pain of having a miscarriage early in her pregnancy and how it affected their decision of sharing the news about future pregnancies with those who loved and supported her. Lori explained,

> My miscarriages occurred in the first trimester, so many of my family members did not know that we were pregnant. After the first miscarriage, we became cautious and tried to not get people's hopes up. It was a trying time after a while; it just got painful and discouraging. In the span of three years we had two miscarriages. Then finally, I had a son after that we had another miscarriage and then I had my daughter. There is a 14 year gap between our son and daughter.

As the participants continued to detail their accounts of miscarriages, the loss of the ability to decide how their families developed surfaced again. Samantha said, "The child that I lost was very sad for me because I wanted four children. It just made me feel like I could not or would not have any more." Karissa pointed out again the fact that she lost her son due to a car accident, although she had support from her spouse and family it did not make it any less painful to deal with the loss.

The anguish these participants expressed about the loss of their children early in their pregnancies was only compounded by additional pregnancy losses, especially for Andell who reported that she had two miscarriages that are documented medically, but believes she may have had an additional one. Of the study participants, Andell was the only one who fell in the 15% of women who did not know the cause of infertility and multiple miscarriages (Poppe, Velkeniers, & Gilnoer, 2007). She was a stepmother to her husband's children, so the family did not initially explore the husband's role in secondary infertility. She recounted her experience as,

> When I first got pregnant, I did not know that I was pregnant. I went to work, and I came home and was lying in the bed. I felt like my monthly cycle was about to begin and I just started hemorrhaging. I rush to the bathroom and a huge clot of blood fell out. I was screaming oh my God! Oh my God what is happening to me! It was then the doctor that told me that I was pregnant. I just did not know. The second time when it occurred, when I got to the doctor that was when he told me I was pregnant because I had no idea I was pregnant. Then when I really had the baby, I was at work, and I got up and felt like I was going into labor. I felt so bad, I held on to my stomach. I said oh my God what is happening. I called my husband and told him I was going to the doctor. At the beginning, it was very, very hard because you have reached so far, you planned to have the baby, you start to buy things for the baby, then you get discouraged. I tried again and when it did not happen, it was very hard for me. Even after I had the miscarriage, people would ask "oh when did you have the baby?" Many of them knew I was so far along in the pregnancy, so they thought I had the baby. Or they would ask, "How is the baby?" Each time they asked, it would get me down.

Although some of the participants were at peace with the miscarriages they experienced, some continued to express wonder of what their child would have become had that child lived. They have acknowledged that infertility and the struggles to conceive has undoubtedly affected them, but they aim to move on and enjoy the years they have with their spouses and the children in their immediate and extended families.

Theme 3: Psychosocial Stressors and Support from Friends and Family

Psychosocial stressors played a role in the lives of the study participants as they dealt with secondary infertility. Stigma surrounding the acknowledgement of the health condition had far reaching consequences for the participants. Many participants realized the benefits of informational and instrumental supports from family and friends, but reluctantly access those supports. As the participants gave their accounts, several sub-themes arose from their stories. These included: (a) stigma and shame, (b) grief and loss, (c)depression, (d) anxiety, (e) support from friends and family, (f) trust in God, and (g) referral to mental health services. These sub-themes and their accompanying sections are discussed below.

Stigma and Shame

All of the participants acknowledged that secondary infertility created some level of psychosocial stressors. Many of them vividly described how their interaction with others made them feel. Jane stated,

> For me initially, I did not see it as a stigma, but after some time it became a stigma for me. When I talked to people, they would ask, “So you have been trying to have kids for how many years?” And you can see how their faces change. It told me how big of an issue it was to them; the way people look at you and the way people see you. It was like you have a sign on you, telling everybody you had a problem. Especially when you join a family or that ex-partner has a new

> wife and she has a kid every year. People are just talking about it when I'm there. Sometimes I am like oh my God; there must be something wrong with me for me to be going through this.

Lori explained how the stigma and shame could have affected her and her inability to have additional children. She too, initially felt pressure to have children until her husband helped her understand that it would take time. Lori pointed out and re-emphasized,

> We place so much value on children, as we should, but sometimes there are other factors that contribute to the fact that women can't have kids. I have been all over world, but I was fortunate to not be surrounded with people who have the mindset that something is wrong with you because you can't conceive.

Samantha pointed out that, "There was so much shame surrounding being infertile. There was a hush in her family when the topic came up." She stated,

> Even in disclosing the fact that you are infertile or talking about infertility has a lot of shame and it is taboo especially among us as a people. I am not sure if it has changed much with the younger generations. In the 80's you would not dare tell anybody that you could not have a baby. Oh the stares, the looks and the whispers it would almost create a sense of paranoia especially among church folks.

It did not create paranoia for Karissa and Janel, who are younger than Samantha, but both stressed that the old attitudes from the church still linger. Janel stated, "I know the bible text all too well. I remember reciting it as a child. It stated that children are a heritage from the Lord. While I believe this to be true; pastors should not shove their beliefs down our throats. Pastors need to be sensitive to others who may not have children."

Even though Karissa did not report having those feelings of paranoia, she experienced stigma and shame when she encountered a long lost friend who had become a pastor. The encounter was not easy and Karissa felt less of a woman after talking to her friend. Karissa explained:

> "No problem, my forever childless friend" were the words written to me by Pastor D. Those words, those words, they cut like a knife. He had successfully relegated my sole existence to being a mother and had caused humiliation and pain. It all started when I recently reconnected with an old friend from church (who I found on Facebook). I was excited to talk to him, because I had not seen him since I was a teen. We exchanged numbers and planned to talk at a later time. During the initial phone call, he jumped straight to the question of "how many kids I had?" I jokingly replied no children. He asked "why?" I responded I have a bunch of nieces and nephews and they keep me busy, but, before I could get the words out he yelled "foolishness! foolishness!" As if to insinuate that caring for my siblings' kids was not fulfilling. My heart sank. Why was that foolishness I asked in my head? I became teary eyed and a lump formed in my throat. How could he? He did not know the pain I had suffered trying to conceive, nor did he know how I had depleted my life savings to cover the cost of infertility treatment? How could he know of the diagnosis of PCOS? I quickly

> pivoted the conversation to my career and how successful I was, that was not enough, and he kept going back to asking about having a damn child. So I hung up the phone. He tried calling back and to avoid further conversation, I texted that I was busy. He replied, “No problem, my forever childless friend.” The words though written, cut like a knife, I could feel the tears trickling down my face, my heart was hurting because somehow, I felt less than because I did not have a child. I fell to my knees in tears, my husband walked in the room to ask what was wrong and I just sat there and cried.

The shame and stigma surrounding the inability to conceive compounded an already challenging situation for these participants. Societal influences and the perception of whether women should have children by certain age only made the feelings of inferiority more glaring, but central to the issue of stigma and shame is the psychosocial factors that negatively affected these women. Feeling less than and not having the support needed made the situation more challenging and tumultuous for the participants. Not only did they experience stigma and shame, but depression accompanied those feelings. The next section discussed how depression affected some of the participants as they tried to deal with secondary infertility.

Depression

Experiencing miscarriage, feelings of isolation and loneliness only compounded the feelings of depression for some participants. Samantha described how emotionally stressful it was because she could not get pregnant. She felt the burden of trying not to disrupt her siblings in their routines in raising their children. She recalled,

> It bothered me emotionally, because my younger siblings were having children. So I was this aunt that was taking care of everybody's children to a point where two of my sisters got pregnant and it got to the point that nobody wanted to tell me when they were pregnant. So there was a hush in the family. It was every month of feeling sad, seeing a period and wanting to have kids.

Andell acknowledged that because she is a private person, she did not share her feelings with anyone and she has only shared this information with me because she felt it was time to share her story. She stated,

> I was very depressed; I did not express my feelings. Even at church when they have children's day, it made me feel sad because I did not have a child. It was very depressing, I feel like all hope was gone. I shut down because it was difficult to handle and I did not speak much about it.

Marian talked about how she almost buckled under the stress of the loss of the baby. When she was able to successfully conceive again she became depressed, and almost ran the risk of losing her second child. She reported,

> It was stressful for me, and for my spouse it was also stressful. I got really depressed when I could not conceive and when I lost the first baby. It was stressful, when I successfully conceived, then I started wondering if I am going to have a miscarriage again. Especially when I got to the nineteen week mark, I made myself sick, I would not eat. I did not realize I was not eating or drinking. I ended up in the hospital because I was dehydrated and I was put on bed rest.

Lori expressed how she blamed herself for the stress that she was under. She even compared herself to other women who had successfully brought their children to term. Lori said,

> I had depression afterwards, because at the time when you are pregnant you don't expect anything to go wrong. So I started asking myself questions like what could I have done differently? What did I do? Was it my fault? There was always that self-blaming, like what is wrong with me? Why can so many women carry kids and I can't? There was always self-blame. What if I had stayed home and did not go to work? No matter how often it happens, I eventually realized did not do anything wrong, because I followed the doctors' orders and it was still hard to accept.

Moreover, India found herself initially unable to accept that she wouldn't be able to conceive again and how that denial affected her. She said,

> I would not say I experienced depression. I was taken aback, and I was very sad. It took me a while to grasp the whole thing and I became very anxious. It has put me in a different light, I am not going to say I am totally depressed, but I am very, very saddened about the whole situation.

The anguish for Jane was unbearable. For most women monthly cycles denote something positive, but for Jane, it was a source of unpleasantness. She stated that she became depressed to the point where she stopped taking care of her own personal needs. Jane recalled,

> I think I was depressed mostly after each monthly cycle. When my cycle came then all my joy just disappeared. I could not even eat, I just cry, cry, cry, and cry. I could not even pray. Sometimes I would say oh my God, I have been praying, I have been fasting, I have been seeing the doctor and yet no answer. My monthly cycle, I think, was my lowest time, I would just go out and just going about my business, you would think I am there, but I am not there, because my mind is just gone… my blood pressure is up and my eyes are blood shot because I am stressed…It also affected the way I looked. I did not care about my own looks. I did not care about putting on makeup or looking good. When I was down, the way I would dress, the way I would look, people would see me and think I was sick. They would ask if I was sick and I would tell them I am ok, but I am just going through that period, where I am so low, and I am just on my own.

Karissa stated that her depression was interwoven with the grief and loss. She stated, "I think I experienced depression, because I was grieving the loss of a child I never knew."

Not all the participants in the study experienced depression, but for those who did, it had a profound effect on how they viewed themselves and how others viewed them. A monthly cycle which indicates the health of the reproductive system contributed to the depressed feelings some study participants experienced. Seeing children play and or engaging in child centered activities gave rise to feelings of depression for others. While the experience of depression was real for some participants, others dealt with anxiety.

The following is an account of those who grappled with anxiety surrounding their experiences with secondary infertility.

Anxiety

In addition to feelings of depression, the participants discussed their anxiety surrounding their inability to conceive. The characterization of that anxiety for each participant was different, but manifested itself in a similar fashion. Andell spoke of always feeling down and overly anxious at times, because they did not understand the psychology and physiology of the body and what was leading to the miscarriages and her inability to conceive.

Samantha described how she experienced high levels of anxiety when she had her period each month to the point, where she tried to hide it from her husband because it increased his level of anxiety. She said,

> When my period came each month, I would say oh God my period came, and I did not know how to tell him. In fact I did not want to tell him, so from that stand point I was feeling anxious a lot because I did not want to talk about it and I did not want the disappointment for him. Emotionally it was a lot, it really was. It made me feel like less of a woman because I wasn't able to fulfill that role. It affected me emotionally.

Being diagnosed as having anxiety only compounded the problem for Karissa, who now is faced with the challenge of conceiving. She reported "I was already an anxious person, I know now my anxiety is attributed to PCOS, but the desire to have another child only heightened that anxiety." Acknowledging that anxiety affected the relationship with her spouse and the ability to have children was poignant for Karissa.

Simone articulated that anxiety was present in their struggle to conceive, but it did not affect their relationship in manner where they lost the strong bond they shared as a couple. She reported,

> I did not really experience that much anxiety, but of course as I did expect, the natural progression is to be a couple, to get married, and have children and I would say to some degree I had some anxiety. Your spirituality also comes into play, where the bible says be fruitful and multiply. You are not multiplying so what is up with that? We experience some anxiety; yes, there was some anxiety but not enough where we were verbally combative or physically combative or withdrawn from each other.

Trying to conceive increased the level of anxiety for some of the participants and created anxiety for others. More importantly, some of the participants were able to tune in these feelings and recognize the underlying causes and make efforts to limit the effects it would have on their health and the health of their spouses. As some participants dealt with their anxiety, there were others who dealt with feelings of grief and loss too. The participants experiences of grief and loss is found in the subtheme below.

Grief and Loss

The subtheme of grief and loss is not only endemic to the initial loss of not having children, but the continued loss of not having children at all. While most participants made some resolution with it, the sense of loss resurfaced when they were out with friends who had children. Or as those friends talked about their children in reverential terms, the sense of loss emerged once again. That loss was further compounded when efforts made to conceive a second time failed. For instance, Karissa knew that she was going through the different stages of grief, but felt like she had no support. She stated:

> I questioned God, and even stopped going to church for a while. I was isolating myself because I felt I had no support from all the women with multiple children. I continued to grieve the loss of the child I knew, but never got a chance to know. Unless you have been through it, you don't know what that feels like.

Additionally, Lori stated that she grieved a great deal when her pregnancies ended due to medical reasons. She stated that "both the loss of the baby and my recent infertility were very isolating, and I did not have the space to express my feelings about this and so I did not really know how to grieve the losses I was experiencing."

Jane spoke about her grief and loss in trying to conceive repeatedly. She said "It's hard to talk about it with people who aren't going through it. So you also feel like you're sort of isolated. Sometimes you just grieve in silence."

Samantha echoed similar sentiments about not being able to share the feelings of grief with others. She explained,

> It's hard to talk to people who have conceived about your experience, they just cannot relate. I mean, at one point, I thought it would never happen. I felt less of a woman, and just that yearning of wanting to and having that experience was a loss in and of itself.

Andell used the words *"it never happened"* repeatedly to denote the loss she felt regarding her inability to conceive again. Coupled with Andell's grief and loss is regret. She explained,

> I was in denial that I lost the baby. I just could not believe it. But the help, maybe if I had help I could have save the baby. When my aunt came over, she took up the baby and she took the baby over to me. I did not want to look at the baby. When they placed me on the ward, the nurse took the baby to me once again and told me to hold the baby and I refused. I did not even feel what my baby felt like. I was so numb that I did not want to touch the baby. I should have taken the baby and held the baby. I have pictures and foot prints of the baby. Sometimes when I am cleaning out the closet I see the pictures, I ask what if? What if? Sometimes my husband will ask me to get him a glass of water and I tell him to ask the child, because we had already picked out her name. We just joke about it. Even years after the loss, I would not have spoken about it.

She further stated that even though she was unable to share in a similar joy of having her own children, she shared those emotions with her nieces and nephews as they move through the different stages of life and celebrate their individual successes.

Grief and loss are endemic to the human experience, but mothers never plan to bury their children or lose the children they have hoped for all their lives. Some of these women had already picked out names for their babies and when they see a child of similar age with the same names, it continues to trigger that loss. Some participants have experienced the stages of grief and have made resolution with their losses, but it does not negate the sense of loss they have experienced. As the participants detailed their losses, it was important to have support from their families and friends. Detailed below are the accounts of the support from Social Networks the participants received during their experiences.

Support from Social Networks

Support from family was crucial in helping the participants struggling with secondary infertility. Many of the participants reported feeling great support from family and friends, but others stated support received was not always positive. For instance, Jane described the levels of support she received from family members as being different from what she received from her friends. Jane reported,

> My inability to conceive did not affect my immediate family members, but it did impact my relationship with my extended family. They wanted me to try everything, like going to a doctor, go to church and pray…to seek all types of help to become fertile. They got upset because they were trying to help me, but I did not see any good reason to seek or take their help. When I was not taking their advice, it strained our relationships. My immediate family has always stood by me. They often say, "It is God who knows everything." My friends would call and tell me they are praying for me or they shared what they found online, and they would say "this is what I saw and maybe it can help you." I have friends who would go to the store and say, "You might need this to help you." I also had friends who would give me a call and at the end of the day, if I was very happy, after they were finished talking with me I felt so sad, because they wanted to give

> me ten reasons why I am not having a child or why I have the miscarriages. What I did was choose between friends who would helped me and friends who when they are finished talking, I felt so low.

India pointed out inadvertently, that she found more support from her friends than her family because of her family's great desire for more children. Her family's desire for more children in the household made her feel at the time that she could not talk to them about her health concerns. In hindsight, she felt she would have received more support from her family had she really discussed her challenges with conceiving. She stated,

> All of my siblings have children. They were happy for me when my son was born. My family was hoping for more children. They kept saying you need to add another one. You need to do this, you need to do that. Some of my friends, I think that they were trying to help. I know there is a lot of empathy when I listen to my friends at times. They try to lift my spirit by saying, "it is a part of life, at least you were able to have one so don't worry about it." I talk to my friends and I have met one other person who is in the same position, so I have support and I use it to comfort myself.

Simone found that being open about her situation helped her with gaining support. She reported that her family offered her different types of supports based on their ability. She found that support for her increased exponentially when she conceived because they knew how long she desired to have a child. Janel and Marian stated that if they needed support they could have found it in friends and family members.

In addition to having a loving family structure, Lori described briefly how she ensured the support she received was positive and helpful for her and her family. She explained,

> My family members were supportive, because it was just my husband and I and our parents. There were a few select friends that were near to us since we were in the military and some had experienced the same thing, so they were very understanding. We try not to surround ourselves with negative people because it has a way of impacting us.

Both Marian and Edith also talked about having a network of friends who struggled with conceiving, and finding solace in their shared experiences. They found that family support, although beneficial was limited. Edith stated that both her and her husband initially did not discuss their struggles with anyone, but as soon as they learned of others having struggles they found more support in their friends.

On the other hand, Samantha discussed how difficult it was initially for her to garner support from family, but her coworkers were great supports. She jokingly added that even her coworkers would help monitor her ovulation and she had freedom to leave work during that time. She posited again that,

> Infertility is something that you cannot discuss with people who have children without it being an issue. They cannot comprehend what you are talking about. You should always talk to somebody who has experienced it. They can empathize, but they do not know what it is like - that yearning of being a mother. You would not tell anyone you had trouble conceiving so how could you garner

> support? As I mentioned even my own siblings did not want to tell me when they got pregnant, so support was minimal. However, at work, I found people were supportive because you become so aware of your body. I would know when I was ovulating and what time to go home and it was very intense.

Two of the women in the study, Karissa and Andell acknowledged that their desire for privacy reduced their desire to reach out to others to obtain the support that they needed. Karissa stated,

> I initially did not share my struggles with anyone except for my husband. It was later that my family and friends said they would have done this or that had they known about the issue, but it is too late for that now.

Andell shared similar sentiments when it came to seeking out and receiving supports. She explained,

> I did not want to speak to anyone. I did not call anyone. It was just me and my husband. I told my husband don't call anyone. I did not want anyone to know that I lost the baby. I eventually called my aunt and she came over. She was the only one I called. I am a private person and so I did not reach out to many people. My family and I, we talked about it and they comforted me. Even then I did not share a lot with them. They encouraged me to keep trying, but it never happened. When I am asked how many children I have? And I reply I was not able to have a child, my sister will correct me and say, "You did have a child." I went through the whole process of having a child; it was just that when the baby was born, the baby died.

Throughout the challenges of life, it is often the support from friends and families that get individuals through the difficult times. As evidenced by the accounts of the participants support from family and friends was twofold, as it was sometimes positive and other times negative. Other participants in the study felt that they could handle their issues on their own but later found strength in sharing their hurts and not carrying their losses on their own. Other participants saw themselves as their own support system. Others use their faith to help them through their experiences. Faith gave some participants hope, even if it meant not having any children. Some of the participants attributed their resolution to a Trust in God; as a result, the subtheme of Trust in God is discussed below demonstrating the ways the participants were able to overcome their struggles.

Trust in God

Trust in God was a resounding subtheme for three of the participants. Having faith and trust in God served as a significant source of strength for these African American women with secondary infertility. For African American women, a strong belief in God is a key component in addressing illnesses and for these participants, secondary infertility was no different than any other illness that required Godly intervention. It was essential for the study participants to acknowledge how important it was to recognize that faith in God could rebuild their broken spirits about not having children or additional children. The participants discussed how they had resolved within themselves that if it was God's will for them to have any children or additional children, then it would happen in His timing.

Lori talked about her husband's faith and how it was his words that strengthened her belief that children would be a part of her future. She explained,

> My husband is a person of faith and he always said when God wants us to have kids, we will. We always believed that we would have kids. It was not God's time yet. Just when you think you won't have any more after our first son was born, then a miracle happened with our daughter. If you have faith and believe that everything will work out with the help of modern medicine, everything will work out.

Jane talked about her strong belief in God and how her family often reminded her of God's Omnipotent, Omniscience and Omnipresent power. She found herself initially blaming God for her many miscarriages and her inability to successfully have a child; however, through the encouragement of others she relied on her faith and she was able to move beyond what was happening.

Andell stated that she accepted her state of being childless because of her belief in God. She knows that God will help her through certain things. She added, "After a while, I felt a lot better. I have to remember that God is alive, and he is going to take me through all of this."

Three participants highlighted their trust in God as one way of helping them to move past their pain. Constant reminders from loved ones served as reinforcement that their trust in God would help them make it through the challenging times. In addition to trust in God, it is also important for the participants to seek additional help through direct encouragement from health providers, as they have been given the medical knowledge to address the underlying causes of secondary infertility affecting the participants.

Referral to Mental Health Services

The psychosocial factors that the participants experienced due to infertility necessitated mental health intervention. Living with the trauma, depression and anxiety as well as dealing with grief and loss spoke volumes about the need for mental health intervention for the participants. Many of the participants stated that counseling services were not offered to them as they went through their experiences. Janel acknowledged that she did not use counseling services because it was not discussed with her.

India also stated that she did not receive any referrals to counseling services from her gynecologist, but she also did not use any fertility treatment either. She felt that more could be done to help African American women in need. She added,

> I think if there was a center where they held sessions or meetings for people to go and discuss and to clearly understand why this is affecting women in our age group. Maybe we could meet every Tuesday evening, not just go to the doctor where they talk to us for five minutes, but a session where they can give an in depth review and everybody talk about their situation to change the outlook.

When asked about use of counseling services, Jane stated that, “I did not receive any referrals to counseling services while going through fertility treatment or for the losses that I had.” Jane stated that she had been to fertility treatment in both Maryland and New Jersey and neither provided her with that option.

Lori's experience being in military placed her in the outlier category, as she reported having access to services albeit that she did not use them. She attributed her resistance to her faith in God and knowing everything would work out. However, she had the option the use counseling services. According to Lori,

> I felt that the medical staff in Japan at the time was more advanced than the medical staff and services in the United States. They offered me counseling at the hospital. The doctors offered and asked if I needed to speak to someone and they had a counselor come to see me, but we opted not to continue the counseling.

Andell expressed strong aversion to counseling. The hospital where she had her miscarriages called her to refer her to counseling services. She did not see the benefit and so she declined. Andell said, "They did not offer me any support. One time they called and asked if I wanted to go into a group thing. I was not for that. My family was enough for me."

The present theme of Psychosocial Stressors and Support from friends and family explored the ways the participants experienced and dealt with psychosocial factors, in addition to their strength to continue with their journey of playing roles and meeting expectations. This section explored the sub-themes of (a) stigma and shame,(b) grief and loss,(c) depression,(d) anxiety, (e)support from friends and family,(f) trust in God and (g)referral to mental health services. These subthemes highlighted the need for appropriate care and services to be rendered so the participants and their families can heal from their hurt because secondary infertility does not only affect the immediate family but also those who loved and care about the participants.

Theme 4: Intervention and Treatment

The current theme of Intervention and Treatment explored various aspects of the medical field, how the participants experienced the health care delivery system and the ways it affected them. The four sub-themes that emerged from the data are detailed below, they include: (a) barriers to using services, (b) recommended fertility treatment services, (c) culturally competent services, and (d) continued use of medical care. Each of these sub-themes is discussed in further details.

Barriers to using Services

One of the pronounced sub-themes found throughout the interviews was related to the barriers to services. Transportation, access to health insurance, lack of referrals and the number of appointments served as barriers in the use of fertility treatments. Jane highlighted how these challenges affected her. Jane explained,

> I had to travel 45 miles to see a fertility specialist. I don't think there are fertility specialists who provided comprehensive care in my community. The number of appointments served as a barrier for me, I had to return for one test result and then set up another appointment for another test. It was overwhelming. I think, if I had good health insurance, then I would have been able to seek more help. A lot of black women don't have good jobs that provide good health insurance. For those who don't have good jobs to get health plans it would be helpful if health shares can give these women access to fertility services, so they would not have to wait too long to seek services. Just by looking at my insurance, I can see how

> expensive it is. So if health facilities can accept the health insurances that black women have then it will lessen these concerns.

Edith spoke as a participant observer with regards to accessing services in her community, because she was never a recipient of fertility services. She discussed her knowledge of fertility treatment facilities in her community. She explained,

> For us, as African American people, one of the challenges is financial. It is very expensive to obtain infertility treatment. I have had a friend who for several years she sought treatment, both for her and her husband. Her husband had a child from a previous marriage and she struggled to get pregnant. She had some surgical procedures. She had endometriosis and some other issues. I know there are infertility physicians, I know downtown you will be able to find some and locally you will be able find some, in the Coral Gables area. These resources are available, but it is the cost that is the deterrent.

Karissa also spoke about the availability of appointment times that fit her schedule more so than her being able to access the services in her community. Karissa stated,

> I am familiar with services in my community that treat secondary infertility. There are several entities here and living in Florida they are easy to locate. There is access to public transportation as well as most individuals drive. For me getting to services took less than an hour. If I could not get the appointments on the days that I needed them, I was given one shortly thereafter.

Marian, India and Lori suggested lack of knowledge as significant barriers in accessing treatment. Marian posited, “I had very little knowledge of my diagnosis of secondary infertility and the treatment options until I spoke to my doctor.” Even so she felt the information was not comprehensive enough and she would get overwhelmed trying to understand the medical terminology when she researched the topic on her own.

India placed the onus on herself and others like her to seek out the knowledge needed to be more informed. She suggested,

> We struggle from lack of knowledge. We are not informed enough. We don’t go in-depth with our research. We stay on the surface and accept the little that is being told to us once we get diagnosed. We don’t go further to find out if this is something we can prevent or if this is a natural part of life.

Unlike the other women, Lori’s experience was different as she benefited from services offered through the military. She openly acknowledged this was an advantage. She passionately argued that African American women need to be informed about options in order to make informed decisions about whether or not they should seek services or accept their inability to have a second child as their fate. Lori suggested:

> I think we need to be informed. In my experience the doctors spoke to me, and I was given a bunch of booklets to know about the process, the cost and every step was detailed about what I could experience or not…information would be the first step in helping others.

For women like Janel, who knew about treatment options she found that in her experience it was fear that served as the biggest stumbling block as well as the lack of support from family and friends. She stated,

> There is a fear that consumes the black woman. When she uses services, there is great disappointment in using services that do not work. It also makes it more challenging without good support systems.

Marian, Andell, Samantha, and Simone raised the concerns of the lack of marketing for fertility treatments towards black women, as well race being a factor in how people access and use services. For instance, Marian stated that "I strongly believe that more efforts should be centered on marketing these services to African American women, so they can gain timely access to resources to assist them." She argued that the belief that may be pervading the medical field is that African American women may have too many children and cannot care for them. She says, "This is erroneous thinking because we use extended family members as informal child care providers."

Furthermore, Andell talked about her race being a determinant in how she was treated. As a woman in an interracial relationship, she found that she received better care when her husband, who is White was present. Andell stated that, "I stopped going to the doctor by myself, or I would immediately call my husband." She felt that her race was a strong predictor in the way she was treated which ultimately led to the miscarriages and the death of her baby.

Samantha stated that she recognized that African American women no longer have to take the word of a doctor. They can actively seek out information on their own by using the internet. But central to her response is the question of African American women's ability to afford and care for their children and does it affect their ability to advocate for themselves if these factors are projected onto them. Samantha said,

> When you are in that position you really have to go in search of information. Is it being spoken on commercials? Not really. Is it that they think that black people cannot afford children? Is it that we are not assertive in getting care? Do we believe what the doctor says, and then it is so. We often hear of people being told that they can't have children and then they do have children.

The intersecting of race and access to care was not lost on Simone. She stated that in her experience there is a direct correlation between being black and the information given about medical treatment. She also added that indirectly diction and appearance also affect how African American women are perceived, thus limiting their access to proper treatment. Simone added,

> When you are black and not being in an environment where people are willing to give you information, there could be a number of reasons: may be its time, too much time to teach you; or maybe it is race, you are not the right color, you don't need to know all of that; or you don't need to have children anyway, you have too many children anyway. They should not make you feel like it is an inconvenience. They should be providing you with as much information as possible and all of the options that are available. Whether or not your insurance is the issue or not, you should know everything. If you have to come out of pocket that choice should be yours. Sometimes they look at you and think that for whatever reason, maybe you

> are not dressed properly or don’t have enough credentials behind your name, they figure you can’t afford the services. I want to hear the whole story and what options are available to me. I would like for everybody to do this, but I don’t want options to not be presented to me because of the way I look, or the color of my skin, or because my verbiage is wrong.

Access to services is critical in addressing the underlying factors contributing to secondary infertility. A myriad of barriers existed for the participants and by extension the African American community at large, these include lack of insurance, support, as well as race affecting the participants’ access and use of these resources. It is important that these barriers are removed so they too can have input in designing their families. If barriers to use services continue to be a deterrent, then poor health outcomes will continue for this population. Health professional must make referrals to appropriate services and let the participants decide if it is viable for them.

Recommended Fertility Treatment Services

The experience of secondary infertility was traumatic for the study participants. This group is already disenfranchised in their access to services. Even those who used services, fertility treatments for some was traumatic. Some of the participants stated they were not offered fertility treatment services, while others actively sought treatment. Janel acknowledged that she did not seek fertility treatment. When asked to clarify, she stated, “I know about the services, every woman ask their gynecologist certain questions or need to know certain options, but I have not done any more beyond research.”

India too stated that she did not receive any referrals from her gynecologist, and she did not use any fertility treatment. India also stated, “I am just doing research right now because I have not fully accepted that I am unable to have other children.”

Marian stated that, “I got pregnant in the time frame given by my doctor so I did not use any fertility treatments.”

The contentment in having one child that was born healthy and without health concerns was enough for some families. Edith stated,

> I never did go to see a specialist for that reason because as I stated, I did not have an idea of saying oh I want two or three children. So I let it go. I did not dwell on it. We really did not discuss it with anyone. It was not something that we necessarily felt that we needed. If happened, it did; if didn’t happen, then ok.

Jane acknowledged that she had been to fertility treatment in both Maryland and New Jersey, but she had actively sought out those services on her own due to her desire to have additional children and save her marriage. She too highlighted the fact that she was never referred to any fertility treatment specialists and had to do her own research to find the ones she used.

Karissa acknowledged that she had actively sought treatment on her own. She did not have any referral from her doctors. She felt the process was one that initially made her feel invisible. Karissa explained that the advice she had been given from her primary care physician and OB/GYN about trying to conceive was that “they both advised me to relax that it would happen since I had not experienced any challenges in having my first child. I was not sent for testing.”

Andell stated that, “I used fertility services to determine why I was unable to conceive after the miscarriages.” She only did so many years later after the doctors suggested that her and her husband get tested. She sought fertility treatment both in Florida and in Jamaica, but as previously stated her husband was resistant to getting tested. She reported, “My experience in Jamaica with the fertility specialist was positive, better than my experience with the fertility specialist in Florida.”

Samantha’s desire to have children fueled her desire to seek out services that enabled her to have her children. Samantha sees her children as the joy of her life and credits her ability to research the subject matter with giving her the children that she so desired. Samantha stated that in her experience, it was her own research that prompted her to see a specialist who then made the recommended referral. She argued, “Black women need to be advocates for their own health and change the stigma that surrounds withholding of health information that can be beneficial to their wellbeing.” She further highlighted how she was first referred to a specialist. She recounted,

> I had recommended services. I started talking with my OB/GYN and they recommended me to a specialist. That was when I was checking out my prolactin levels. I would do my own reading and when I brought it to the attention of my OB/GYN and he recommended a fertility doctor to me. I find that black women don’t want to share things like those. I find that other ethnic groups are more open to sharing information. I don’t know if it is cultural or if it is a thing of shame. I guess it has changed over the years because we realize it did not make sense for us not to share information.

Lori also sought the help of a fertility specialist, which she found through recommendations from friends. She stated,

> There was a time right after our son; we tried to figure out what was the problem, why I could not conceive again, and why certain things couldn't happen. They recommended IVF; we went and got all the information. We saw the doctor and the doctor wanted to do an operation. On the day that it was scheduled, my husband and I, we talked about it and decided not to go that route, and couple of months after that I conceived my daughter.

Access to services includes a concerted effort, shared information and support on the part of the providers. If the participants are not being referred for services, they are more than likely to have their health concerns dismissed or face implicit biases in the ways health professionals respond to their needs. Of all the study participants, only two could openly acknowledge that they were referred for services. This raises concerns about what other health factors affecting the lived experienced of the study participants and by extension other African American women are occurring because health concerns are being dismissed by health professionals. The lack of continuum of care in meeting the fertility needs of African American women was evident, but this also shed a spotlight on whether these services were culturally competent in the first place. In the next section, the participants shared in their own words their experience with culturally competent services.

Culturally Competent Service given by Providers

The study participants continued to use the medical services with the hopes that they would eventually find physicians who were culturally competent to meet their medical needs. During their journey in dealing with secondary infertility, many participants had mixed experiences with service providers. For instance, Lori used the physicians both in the USA and abroad. She highlighted the fact that her experience with providers in other countries was better. She said this of her experience abroad,

> I believe my experience was a positive one that was in the early 2000s, so they had a lot of studies and a bunch of stuff about my condition and they provided me with information. Everybody was very nice, oh again my experience was done when we were not in the states; we were overseas when I was stationed in Japan. My IVF experience was seeing a special doctor in another country. It was easy to access the services if you have money. At the time we were military so whatever I needed, I was able to access care.

Similarly, Jane recounted her experiences with fertility treatment in both Maryland and New Jersey. She reported a more favorable experience with the doctors in Maryland. Jane explained,

> I like my services. I liked when you are there, but I did not like that you keep making calls after calls, because they can't respond to you right away. They explained to me that they just have so much to do. The appointment times were so long. I like that I did not have go elsewhere, everything was done right there. When I was in New Jersey, I would have to go to a different hospital. The staff in

> Maryland gave me so much time, I could talk, and I felt comfortable. They listened. I liked that they listened, and it showed me that they were doing this for a long time.

Samantha recalled her experience using the health facilities in Florida. She stated, “The staff was good; they were very nice, very supportive. They started with testing temperature and taught me how to monitor my ovulation.” She was pleased with the services she experienced and would recommend them to others at that time. Since it was a while ago, she could no longer speak for the quality of services and their ability to be culturally competent in service delivery now.

India did not use fertility treatment services, however, she reported that she wants to learn more about secondary infertility, but should she use the fertility services, the extent of cultural competence would include not labeling her and gently walking her through the process. She said,

> As of now, I am doing my research on services available for secondary infertility. My intention is to continue seeing my doctor, so that he can explain more to me. I don’t want to be dwelling on the subject because it hurts. I don’t know of any service providers in the area. I wouldn’t want to be labeled as the person who can’t have any more kids, but that the doctor will gently explain to me that there might be a possibility, even though there is not one right now. Just be genuine and not forcibly tell me that it is the end of the road for me.

Not everyone had positive experiences using the health care delivery system. Some found the providers treated them more as paycheck instead of a person. Karissa recalled her unfortunate experience during her first round of fertility treatment. She later sought a more appropriate provider for her second round of fertility treatment. She said:

> The first location I visited did not make me feel valued. I felt as if I were just another number. The receptionist was cold when I asked her questions and even in discussing the cost of the service, she was adamant that I pay upfront right now before moving any further in the process. She also assumed that I did not have insurance because she asked me did I have insurance. For the other patients she asked them for their ID and insurance card. I left there feeling devalued and annoyed. I never went back. The second location made me feel more welcome. The physical structure was inviting, the receptionist was patient and the financial coordinator was very respectful. Talking to the doctor placed me at ease.

Simone too, recounted her experience as one that was unpleasant, and she wished she was more informed and sought the opinion of other health care professionals. She said this of her experience,

> No, no, I never felt comfortable and I did not know enough going in. Now that we have access to information via the internet, you can google everything. I did not know what to say from what not to say. I just knew I wanted to be checked and when it was his turn, he wanted to be checked. I think people sense what you know from what you don't know. I did not have the information, and I did not want to ask because I was at the mercy of the health professional. It was uncomfortable, it wasn't a happy time. If I had to do that all over again, I would have asked so many questions and would have had more than just one opinion.

Andell recounted her experiences with the hospital, the local clinic, and her own gynecologist. She started by discussing her first miscarriage and how she felt that their negligence and lack of cultural awareness created far reaching health consequences for her even today. In her own words, she emphatically explained how she felt she was mistreated,

> No way, no way, not at all, no way. Even when I went to the hospital I was neglected. First of all, I don't know the procedure at the hospital, but when I went there they brought me straight into the delivery room, it wasn't time for me to have the baby. I thought they were taking me to the emergency side so that I could see a doctor. I did not get to see a doctor until hours! hours! This is the part I do not like getting into because it brings back too much sad memories. When I went to the doctor during my second pregnancy, I was not aware that I was pregnant; they did all the check up and the urine test. I told them I was trying to get pregnant. And nothing! I don't know if it was their mistake or what happened. When I was leaving, I remember I got to the car, opened the car door and got into the car. Then one of the girls ran out of the office and called me, saying "Andell come, come." I asked what happened, because she scared me. The girl said, "Come, the doctor wants to speak to you." I went back inside and that was the time, the doctor told me that I was pregnant. I said to myself oh my God. Now I become over protective, I became scared to drive home. I went back to work.

Andell’s story does not end there, as she assumed it was a simple mistake with the doctors who initially cared for her. She detailed more descriptively her experiences with medical staff at the hospital and highlighted the plight she faced as a woman dependent on a system that did not see her worth. Andell’s retelling of her story was raw with emotion of sadness, anger and disbelief. She recalled,

> Then one day I started having serious pains and in the night my husband took me to the hospital. I was in so much pain and they totally ignore me, totally ignore me. I started spotting and eventually I went in and they gave me IV fluids. They did an ultra sound, where they said, “the baby was active, you are pregnant, everything is alright, the baby is ok.” I asked why am I hemorrhaging? I was still feeling pain and every now and again I am still spotting and heavily too. One doctor said maybe it was a twin and you lost one. They sent me home and placed me on bedrest. A few days later I was lying on the bed and my water broke, because it wasn’t blood and I was rushed to the hospital, these three ladies put me on a bed and that was it. They put a catheter in and when she returned, she placed me in a wheel chair because she was taking me down to ultrasound. I said to her, I feel like it was sticking me, I don’t think it is in properly. I said to her no, I can’t stand it. After they finished the ultrasound, they told me everything was ok, and they put me back in the room and the nurse came. I don’t think she deflated that thing properly because she pulled the catheter so hard I am telling you until this day I have problems with my bladder, because of how hard she pulled that catheter out. I was there in pain, pain, pain, and next thing I knew the nurse

rushed into the room. I was no longer feeling a lot of pain because the baby was coming. They kept yelling “you’re gonna have the baby now, you’re gonna have the baby now. Sign this, sign that.” Until this day, I do not know what I signed. Before that they never came over and checked on me and I was there crying for help. They pushed me into the labor room and she left me all alone, all alone. My husband came, he was there with me, I said honey “please go and call them the baby is coming out.” He went, and he called them and when the nurse came, it appeared that the baby was stuck, and she was dragging the baby so much, I was pushing, and the baby was not moving. She was being very rough, very rough, very rough, very rough, very rough, very rough, until the baby eventually came out. After that I was unable to pass the after birth on my own. She told me I had to wait for the doctor to come and I was there waiting, and waiting. I waited, I waited, I waited, I waited, I waited for hours when the doctor showed up, he told me he was not on duty and the doctor that was on duty was unable to come, so they called him, and he had to show up. I think they did not tell him the situation that I was in. I don’t know. He spoke to me about it and let me know what went on and what was going to happen. He is talking, and I don’t know what he is talking about. All I am saying is help, help, help me, just help me, please help me. He said ok, I am going to put on a gown and he went and came back. He said if I don’t get it out I am going to have to take you to the operating room and they will have to do a cesarean cut and take it out. I am there praying to God, help me to pass it, help me to pass it. I already have the baby, I don’t want to be cut again. I was able to

> pass it and they didn't even give me anything, it was long after the nurse said to the doctor let's give her some antibiotic. I think they gave me some antibiotic. I don't remember, once I knew I lost the baby, I blocked out everything. The treatment I received at the hospital was zero.

Andell harbored regret about not using other medical facilities to meet her medical needs. The lack of awareness, and not being able to find competent providers to care for her health, placed her at significant risk. Andell's experience, although an exception for the participants, is not an exception for many African American women. It is with this understanding that she has decided that she will no longer use medical providers in the United States. She has resorted to seeking medical treatment in her parents' native country of Jamaica. Andell explained:

> Until this day you will never get me to go back to that hospital. When I am passing by that hospital my body just tenses up. I have not been back on the compound. When I hear that someone is in that hospital, I said no not me; I am not going over there. I have never, ever been back on those grounds. Even now I have never been back to a gynecologist in the U.S. If I need to have anything done, I go to Jamaica. I do my Pap smear and mammogram there. I am very comfortable with my doctor and he makes me feel very comfortable.

Summary

This section of the study explored the various themes that were identified in the interviews conducted with 10 African American women on their lived experiences of secondary infertility. Four themes emerged from these interviews, as well as many subthemes. The four major themes highlighted in the interviews included: (a) defining family and adjusting to the change in definition of a family, (b) experiences with secondary infertility, (c) psychosocial stressors and supports from friends and family, and (d) treatment and intervention.

The accounts from the study participants showed the commonality as well as differences in their experiences of secondary infertility. The participants experience strong emotions pertaining to their losses as well not being able to accomplish the role of being a mother for the first time or having additional children. Many of the participants face the challenge of sharing information with their birth children about how secondary infertility has affected their ability to have siblings. Additionally, many participants found that they could not connect with other women who had children because of the lack of understanding. Moreover their stories showed the barriers when seeking health care, the lack of knowledge regarding secondary infertility and the inability to access mental health service to stave off the feelings of hurt and loss.

The subsequent Chapter addressed the analysis and interpretations within the context of the effects of secondary infertility on African American women. It discussed the importance of participating in research centered on improving access to health care delivery services aimed at improving health outcomes for African American women. Additionally it highlighted recommendations for different studies centered on increased responsiveness to the health care needs of African American women.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was (a) to describe the lived experiences of African American women diagnosed with secondary infertility, (b) to give insight into the subjective understanding and experiences of these women, and (c) to identify any unmet clinical needs for this population. The nature of this study allowed for the identification of the epidemiological, clinical, and psychosocial effects of secondary infertility among the participants, their relationships with their social networks, their differing and unique experiences.

To understand these experiences, I interviewed 10 African American women using a semi-structured questionnaire developed through pilot testing. The questions were designed to capture the lived experiences of African American women with secondary infertility. The lived experiences shared by the participants contribute to the body of research on the health and health outcomes for African American women. I audiotaped, transcribed, and entered the interviews into NVivo, allowing for themes and subthemes to emerge. Four themes emerged from the data analysis, and I further divided each theme into the subthemes I presented in Chapter 4. In Chapter 5, I discuss the relevant literature pertaining to my interpretation of the findings, identify limitations of the study, offer recommendations, note implications, and draw conclusions.

Interpretation of the Findings

The findings of the study highlighted the need for increased awareness and understanding of the challenges surrounding secondary infertility for African American women. The data analysis highlighted six major factors for African American women with secondary infertility. These factors were: (a) social support played a role in the participants' response to secondary infertility; (b) infertility continues to be viewed as a woman's issue; (c) participants experienced a lack of exuberance surrounding pregnancy; (d) the participants experienced feelings of inadequacy; (e) there was a low use of mental health services; and (f) participants encountered a lack of culturally competent services. These factors are important in the interpretation of the lived experiences of African American women with secondary infertility.

My findings aligned with those of Beckes and Coan (2011) and Berkman and Glass (2000) who argued that social supports served as buffers from life's normative and non-normative events and provided access to resources that would otherwise be unattainable. Social support for African Americans is a buffer for many health concerns. Some of the participants in the study did not access their social support because of fear of showing vulnerability during a time when most women should be excited about becoming pregnant and raising their children. The experience of secondary infertility magnified the sense of damage to their ideal sense of womanhood. Therefore, the participants chose to remain silent about their experiences instead of seeking supports.

The level of interconnectedness and interdependence that is unique to African American population eluded some of the participants because of the nature of the health challenge they experienced; as a result, they isolated themselves from their supports (see Costello, 1982). Sharing their experiences with social networks was more challenging for some participants because other members of those networks had accomplished the goal of having more than one child or children that were still alive.

Social networks meet a variety of individual needs through group identity, adding value and a sense of worth to those participating in these networks (Beckes & Coan, 2011). Some participants could not access the group identity, added value, and self-worth that social networks provide because of the constant reminder that they had failed to achieve the ideal role of being a mother of more than one child or to a child that is still alive. The participants who benefited from social support nonetheless had to make a concerted effort to recognize toxic social networks, extricate themselves from those toxic relationships, and maintain the social networks that offered emotional, instrumental, and informational support and appraisal (see House, 1981). The benefits of participating in social networks can only be attained when individuals access those social networks.

Infertility continues to be viewed as a woman's issue in society. The culture, structure, and development of fertility programs reinforce the burden of dealing with secondary infertility as a woman's issue. Some participants had internalized the idea that the challenge of conceiving stemmed solely from their bodies. According to the participants' accounts, it was by chance that some of their partners learned of their role in contributing to secondary infertility. It was only then that some of their spouses' began participation in fertility treatment. However, while the participants were willing to continue treatment, their spouses were not always willing to engage or continue with the process. Mundigo (1998) stated that men's participation in reproductive health involved their willingness to see themselves as both partners in the process with their spouses and clients in need of reproductive services. Singh, Bloom, and Tusi (1998) attributed the low participation to lack of knowledge, perceived shame, and embarrassment; as a result, there is an inclination to not seek medical treatment. The lack of awareness, misinformation, religious beliefs, and traditional roles placed the burden on women to seek care in effort to conceive. Knowledge of the reproductive systems and changes to how males are socialized in society may improve the attitudes of some men to actively engage in fertility treatment.

My data analysis showed that the participants' desire to have additional children was wrought with anxiety and fear. The exuberance surrounding pregnancy was lost when pregnancy was finally achieved for some participants. Some couples were reluctant to share the news of conception with extended family and friends because of fear of losing the unborn child. The expressed fear of losing the unborn child or having lost a child prevented some participants from seeing themselves as parents. Those participants easily discounted the idea of being a mother because their child had not lived after being born. Some required constant reminders that their ability to parent is independent of having children. Some participants focused intently on a successful delivery to the point where they became ill. Many attributed this to previous miscarriages, but they had not realized that focusing solely on a successful pregnancy and delivery placed both themselves and their unborn child at risk, thus failing to fully participate in the experience of being pregnant and preparing for the child's arrival.

Inherent to the pain, suffering and shame secondary infertility brought, was society's perception of the participants and how they were defined. Many of the participants saw themselves as less than, while others reported not feeling like a woman, and many experienced loss of self-esteem and low self-efficacy. Ashing-Giwa et al. (2004) stated that women experience a sense of damaged womanhood, flawed femininity, loss of the concepts of family roles, and loss of women's roles when they are unable to have additional children especially if the first child did not live. The participants had expectations to have additional children, who in turn would care for them as they aged. These children would also carry on the family traditions and practices, but secondary infertility has thwarted this ideal. This loss according to Batool and de Visser (2016) creates a crisis of failing to meet expectations which is described vividly in the participants' accounts.

In addition, the shared experiences of connecting with other women is impeded by secondary infertility, as women with children do not understand the sense of hurt or loss secondary infertility brings for those women who did not experience live births and could not have additional children (Andrews, 2010; Mogobe, 2005; Obeidat et al., 2014). The sense of loss is magnified for the participants when they see other parents engaging with their own children or they are asked about the number of children they have. To mitigate the pain, participants who successfully had one child focused on the successes of that child. Other participants increased the level of affection displayed to their child if their child was too young to achieve any major successes. Participants who did not successfully have any children focused their energy on children in their extended family. Lee et al. (2009) and Mogobe (2005) stated that a chance for inner transformation and spiritual growth occurs in the lives of individuals as they endeavor to add meaning to their lives when they experience secondary infertility regardless of having a previously successfully live birth or an unsuccessful one. Some participants endeavored to add meaning to their lives through adoption, pursuing missionary endeavors or career advancement, as their chance for inner transformation and spiritual growth.

Perceived stigmas had implications for mental health and wellbeing for many of the participants. The participant did not discuss their emotional and personal feelings surrounding secondary infertility with mental health professionals because of the stigma associated with use of these services. Cultural beliefs also served as a deterrent, impeding the participants in actively seeking out services and participating in mental health services when offered. Alvidrez (1999) pointed out that the perception that mental health services serve only the mentally ill prevents many African American women from seeking counseling services to address their multiple losses. Religious beliefs for some participants affected their decision to seek counseling services. Landrine and Klonoff (1994) discussed that many subscribe to the idea that mental illness has supernatural causes. Therefore, the participants spoke about having faith which served as a stronger buffer against the unintended psychological consequences of secondary infertility. Some of the participants seemed to accept their diagnosis of secondary infertility, as well as the pain and suffering that accompany the loss of having additional children, as normal or a part of God's plan.

According to Wolf et al. (1990), women who had conceived were not motivated to participate in fertility treatment. But this is in direct contrast with the participants' reports. Although many participants confirmed that they did not seek a second medical opinion or question their diagnosis, this was not because of lack of motivation or lack of health insurance, but due to an inability to navigate additional services, medical bias, and a lack of confidence in the subsequent medical advice (see Armstrong & Plowden, 2012; Chandra et al., 2014; Gamble, 1997; Misser et al., 2011). Seeking additional medical advice could possibly lessen the effects of the diagnosis for those participants who did not use these services (see Batool & de Visser, 2016).

The perception that doctors are experts and should know what is best was dethroned in the responses given by the participants. Discerning that doctors do not know their bodies, nor do they care about black women's bodies, was a sobering awareness for some participants. Burgress et al. (2007) suggested that stereotype suppression has unintended consequences for minority populations. Many participants also experienced stereotype suppression leading to unintended consequences for the both themselves, their unborn child, and in their ability to conceive a second time. The lack of self-determination in one's care was also highlighted as the participants perceived that they were in less control over medical care, or the medical decisions that were made. They felt like participant observers in their own medical care because medical terms were not explained in everyday language and alternative treatment options were not offered. This confirmed the research put forth by Agency for Health Care Research and Quality (2012) and Ashing-Giwa et al. (2004) stating that African American women are more likely to report that their doctors do not listen to their concerns.

The historical mistrust of doctors also contributed to their hesitancy to seek additional care (Gamble, 1997). Doctors were perceived as not caring or not listening to the concerns being expressed because of the participants' phenotypic expression (Agency for Health Care Research and Quality, 2012). One participant aptly addressed this issue when she stated that she did not want to be judged because of her skin color, having poor diction, or how she was dressed. The findings confirmed that race and ethnicity played a strong factor in the perception and treatment of the participants. The African American culture has survived through a strong level of interconnectedness with family members and friends and dealing with racism and secondary infertility compelled some participants once again to draw on that level of interconnectedness.

Access to culturally diverse and culturally competent services was of great concern to participants in this study. Brach and Fraserirector (2000) argued that by having diverse staff, providing appropriate linguistic supports, and having strong knowledge of community resources that do not fit the main stream medical model, all serve to bolster the delivery of culturally appropriate and culturally competent services. The health care delivery community did not respond to the needs of some of the participants in a culturally sensitive way. According to Burgess et al. (2007) more positive interactions with individuals of different ethnicities in different clinical settings can help to reduce bias in treatment received. Cultural competence in health care delivery was found to be more favorable in other countries. Receiving first class health care services in other country was poignant for some participants, because the services were more inclusive of shared cultural beliefs and improved communication. A welcoming environment and family supports were encouraged at these doctor's visits thus promoting culturally appropriate or culturally competent services.

Limitations of the Study

There were three limitations of the study. These included the development of the semi-structured interview questions, the sample size and sample selection, and the method of data collection. The first limitation of the study was the use of semi-structured interview questions. The semi-structured interview questions were newly developed and the questions were formatted to garner the lived experiences of African American women with secondary infertility. The semi-structured interview questions were pilot tested with women of similar race and ethnicity as the study participants. Therefore, the semi-structured interview questions may not be conducive to explore the experience of women of a different race and ethnicity, as their experiences do not mirror those of African American women.

The second limitation of the study was sample size and sample selection. The study sample consisted of 10 African American women. Qualitative research study design allows for small sample sizes (Creswell, 2009); however, these 10 participants may not represent all African American women experiencing secondary infertility. The study participants were recruited through a snowball sample, mostly from others, who saw, read or heard about the advertisement. Therefore, assessing the level of willingness initially to share their stories of their experiences with secondary infertility is a limitation of the study. Moreover, most of the study participants resided in urban areas or had previously used health care services in urban areas, where there is a greater level of access to health care services. It was difficult to determine if African American women in rural areas would have had similar or dissimilar experiences with service providers or seeking treatment.

The final limitation of the study was the method of interviewing. This may have affected the amount of information shared by the participants. The majority of the interviews were conducted via the telephone. It was difficult to determine whether the participants were more forthcoming because the interviews were done over the phone or if a face-to-face interview would have garnered more information from all of the study participants. Additionally, the interviews were conducted over the phone; therefore, the research did not capture two components. These include the nonverbal cues that the participants gave as they told their stories and all the emotional reactions of the study participants as they shared their experiences. While these two components could not be captured because the interviews were conducted over the phone, the absence of the information does not negate the accounts given by the study participants because their stories painted a vivid picture of their experiences.

Recommendations

There are several recommendations for future research on secondary infertility in the population of African American women. Mundigo (1998) stated men's participation in reproductive health involved their willingness to see themselves as partners in the process with their spouses as well as clients in need of reproductive services. Therefore, this recommendation involves using education and media advertising in challenging and changing the traditional views of what constitutes a man or a woman's roles in participating in fertility treatment. The traditional gender roles are learned early in life from interactions with various individuals and institutions. These roles can be changed by holding rotating lunch and learn sessions at various organizations to discuss the treatment options for infertility. Local fertility experts can work with local organizations and provide these sessions free of charge, and in turn increase knowledge and reduce stigma. Moreover, local fertility experts can create public service announcements or use different marketing techniques to get the message out to the public. These messages must depict individuals who are representative of all ethnic groups in order to increase awareness and promote education. Therefore, with education and the use of media advertising, the stigma associated with seeking and participating in fertility treatments can be descreased.

Across the spectrum of health, health outcomes, health care access, and health care delivery, African American women fair far worse than women of other ethnicities, even when socioeconomic status is controlled (Goza, Stockwell, & Balistreri, 2007; Navarro, 1990). The lived experiences of secondary infertility fell into the spectrum of poor health outcomes for African American women. Their experiences and their stories have not been told nor have they been heard by the research community; therefore, they are largely absent from the research. As result of the findings in this study it is recommended that subsequent qualitative studies explore African American women’s understanding of the health care delivery system and effective ways to navigate the system in order to gain access to the appropriate care to meet their health care needs. These studies need to include African American women in rural areas as well as urban areas. A clearer understanding of these factors, independent of the already known medical bias, could explain why many African American women hesitated to seek treatment despite wanting more children. This study should also focus on ways to empower African American women to advocate for themselves by recognizing barriers to accessing care, obtaining more than one medical opinion, and identifying supportive services that promote advocacy efforts.

It is also recommended that educational curricula for physicians place strong emphasis on rendering culturally competent care to African American women. This stemmed from the African American women not feeling valued or listened to when seeking medical care (Agency for Health Care Research and Quality, 2012). It reinforced for the population that their bodies are not valued (Gamble, 1997). Changes in the curricula should emphasize the need to treat African American women and women of minority status with respect, dignity, and compassion when caring for their health care needs. The curricula should also be centered on empowerment through active and reflective listening as well as validating their concerns so African American women know they have been heard. In addition, it must address ways to make timely and appropriate referrals to maintain the continuum of care. Health care professional neglected to make timely and appropriate referrals as evidenced by the participants' accounts. Many of the participants were not referred to a specialist to obtain treatment for secondary infertility and those who sought treatment were already in the health care field and understood some of the clinical processes. This could improve and reduce the deep distrust exists between the African American Community and medical professionals, stemming from the historical experiences of African Americans (Humphrey, 1973).

It is also recommended that institutions responsible for training medical staff and health care delivery systems to conduct an analysis of their newly trained as well as seasoned physicians to ascertain their understanding and ability to render services to a diverse population. Moreover, there is a need for physicians to change their attitudes in how they treat African American women. Assessment of physicians' understanding and attitudes towards African American women with secondary infertility could improve outcomes.

Partnership between the mental health community and the religious community to address the mental health needs of African American women and the African American community at large is recommended. The use of mental health services to address underlying mental health concerns is important to reduce stigma (Ward, Clark, & Heidrich, 2009; Ward, Wiltshire, Detry, & Brown, 2013). To address the mental health needs in the community, the religious community must actively work with mental health providers to hand out information about services while maintaining the religious principles and values that are important to African American women and the larger community. A high level of visibility is needed between these entities for the community to buy in to the benefits of using those services. The erroneous belief that mental health has supernatural factors inadvertently dissuades the African American community from benefitting from these services (Landrine & Klonoff, 1994). Changing this belief can be achieved by inviting mental health providers to church functions, highlighting the benefits from the pulpit, and highlighting mental health nuggets in the church bulletins. Consecutively, mental health providers can provide education centered on communication for the religious community to educate them on how to respond to women who do not have children and break down the stereotypes that exist about women who are unable to have any or additional children. This will challenge the sexist attitudes, and poor communication patterns including, but not limited to hostile remarks, and unwanted advice often used to chastise women who are unable to fulfill some “divine plan” of having children.

Additionally, it is highly recommended that a comparative study be done on the benefits of educating and emphasizing self-care in the African American community to address physical health as well as psychological/emotional and social wellbeing. Galhardo et al. (2013) and Neff (2008) highlighted that self-care is crucial to helping individuals deal with psychological stressors. Mental health services must be geared towards teaching self-compassion (Copeland & Snyder, 2011; Ward, Clark, & Heidrich, 2009). Self-care in the form of actively using mental health services and alternative therapies such as reflexology, massage therapy and other therapies to deal with the emotions associated with secondary infertility are needed. Many of participants had multiple miscarriages, intra-uterine fetal death, and intrapartum death, but did not actively seek services because they felt they could handle it on their own. The desire for African American women to remain strong in the face of trauma is deeply rooted in historical experiences of slavery, racism and prejudice, but it continues to negatively affect their health and wellbeing long term and may very well have implications for the genetic information passed on to their children.

Andrews (2010) reported that some women do not feel connected to the motherhood experiences or they were not viewed by their contemporaries as mothers. Some participants who experience primary infertility and later dealt with secondary infertility found it difficult to discuss their sense of loss with other women who experienced only secondary infertility or those who had no experiences with infertility. It is recommended that a comparative analysis on increased awareness, the differences and psychosocial needs as well as the medical needs for women who suffer from primary infertility, as well as secondary infertility or fecundity. In addition, the study should explore attitudes and beliefs towards women in the aforementioned groups in an effort to improve tolerance among women across groups.

Implications

Social change implications of this research are addressed at three levels. These levels include the individual, community and society by providing new insights into the lived experiences of African American women with secondary infertility. These implications are discussed below:

Individual

The experiences of secondary infertility were unique and diverse for each participant. Their shared experience is important for social change because it moves that experiences from the realm of nonexistence to the forefront of research. The results of the study also reinforce that secondary infertility is not an isolated experience, although it can be isolating. The documented experiences normalize and validate the physical and psychosocial stressors that are associated with secondary infertility. It also served as impetus for individuals to advocate for themselves to ensure that quality medical services are rendered. The study also promoted the need for interventions to be tailored to the individual instead of to a group, because individual differences exist within and across homogenous groups.

Community Level

The social change implications for this research pertained to the services rendered by professionals across the spectrum of the health care delivery system. The African American community has a long history of maleficence under the guise of research (Gamble, 1997). Therefore, a high level of trust must be built between the African American community and mental health providers. Promoting social change involves educating the community and working with community leaders and gatekeepers to share information about the benefits of participating in mental health services. Building this relationship will require numerous interactions with community leaders and gatekeepers before the information will be shared with the community at large. It is important for mental health services to be transparent at all times in their interactions with the African American community to reduce the high level of distrust. Trust can be easily eroded if the community perceives duplicity.

Health care professionals’ proficiency in coordination of services is also important to promoting the health of individuals, which in turn impacts the health of this population. There is a need for increased awareness among health care professionals to be knowledgeable of supportive services that are culturally sensitive and culturally competent in the community. This can be achieved through culturally sensitive communication. Health professionals must recognize that communication is a process of awareness, where reflective listening, validating concerns, and providing opportunity for additional questions to be asked; only then can health professionals increase understanding and tuned in to the needs of those seeking services. Moreover, the use of Health care literature as a means of communication must be linguistically and culturally appealing. Individuals must see themselves in the health care literature in order to accept the information presented.

The health care delivery infrastructure must also be in place to meet the existing needs. The availability of appropriate fertility services, the distance of these facilities and the number of competent providers who can provide correct medical diagnosis contributing to successful outcomes. Treatment and disease prevention is an important factor in promoting social change, therefore, resources must be allocated for recruiting health care professionals and building the infrastructure consisting of health centers, and other facilities that are local and community centered to promote the continuum of care for those seeking fertility treatments.

Societal

Societal and policy related social change implications of this study include engaging in challenging conversations and discussion about policies that continue to support and promote health disparities in minority communities. Policy changes are needed to create supportive laws that promote receptive environments for the development of innovative health services to meet fertility needs of women, reducing the invasiveness of the procedures, and promoting the use of fertility treatment services by men. Policy changes at the federal level and state level are needed to encourage insurance companies to provide comprehensive services to participants in need of fertility treatments. The federal mandates and state laws must be similar so that insurance companies cannot use loop holes to increase cost for services or provide less comprehensive fertility treatment across state lines. Insurance mandates and the excessive cost for fertility treatments needs to be re-evaluated as well as finding creative ways to allocate funds for research and innovative technologies to reduce the lack of access to infertility treatments.

Conclusion

This study focused on the lived experience of African American women with secondary infertility. The lived experiences of secondary infertility fell into the spectrum of poor health outcomes for African American women. Their experiences have not been documented, therefore they are largely absent from the research. The nature of the study allowed for the identification of the epidemiological, clinical, and psychosocial effect of secondary infertility in African American women and their relationships with their social networks. The themes that emerged from the research highlighted the need for further exploration of the health and mental health needs of the African American women and their community at large.

Moreover, there is a need for increased awareness and understanding of the challenges surrounding secondary infertility for African American women. Secondary infertility continues to be viewed as a woman's issue. Some African American women were confronted with the daily reality that they were unable to fulfill the role of being a mother again because of secondary infertility. As a consequence of their experience, it was difficult to bond with other women who had with children. Obtaining support was challenging for the participants as many felt it was a private issue, and they dealt with the pain on their own. Based on the accounts given, it is evident that the experience of secondary infertility is sometimes isolating. The participants experienced feelings of inadequacy, low use of mental health services, and the lack of culturally competent services when accessing and using health care services. Even so, the sharing of and validating of experiences can serve as an impetus to increase advocacy skills for other African American women - ensuring that they are securing the medical help needed.

To accomplish this goal, health care professionals' proficiency in coordination of services can alleviate some of the anxiety for those needing medical help to address secondary infertility. Culturally competent and culturally sensitive services are needed to meet the diverse needs of the population who experience secondary infertility. It is important that the appropriate health care delivery infrastructure exists to meet the needs of African American women who struggle with secondary infertility. Policy changes are also needed at federal and state levels to promote proper access to the services that can reduce the morbidity tied to secondary infertility.

References

Abenhaim, H.A., Azziz, R., Hu, J., Bartolucci, A., & Tulandi, T. (2008). Socioeconomic and racial predictors of undergoing laparoscopic hysterectomy for selected benign diseases: Analysis of 341,487 hysterectomies. *Journal of Minimally Invasive Gynecology, 15* (1), 11-15. doi:10.1016/j.jmig.2007.07.014

Aisbett, D.L. (2006). Interpretative phenomenological approaches to rural mental health research. *Rural Social Work and Community Practice, 11*, 52-58.

Agency for Healthcare Research and Quality. (2009). *Emerging lessons: Participant recruitment for research*. Retrieved from https://healthit.ahrq.gov/ahrq-funded-projects/emerging-lessons/participant-recruitment-research

Agency for Health Care Research and Quality (AHRQ). (October, 2012). *Disparities in health care quality among minority women: Findings from the 2011 national health care quality and disparities report* (Publication No. 12-0006-3-EF). Retrieved from https://archive.ahrq.gov/research/findings/nhqrdr/nhqrdr11/minority-women.html

Al-Safi, Z.A., Russ, P.D., Post, M.D., & Polotsky, A.J. (2013). Adenomyosis with a uterine septum in a patient with secondary infertility. *Gynecological Endocrinology, 29*(8), 804-806. doi:10.3109/09513590.2013.801445

Alsop, G., & Tompsett, C. (2006). Making sense of ‘pure’ phenomenography in information and communication technology in education. *ALT-J. Research in Learning Technology*, *14*(3), 241-259. doi:10.1080/09687760600837058

Alvidrez, J. (1999). Ethnic variations in mental health attitudes and service use among low-income African American, Latina, and European American young women. *Community Mental Health Journal, 35*(6), 515-529. doi: 10.1023/A:1018759201290

American Society for Reproductive Medicine. (2014). *Fact Sheet: Stress and infertility*. Retrieved from https://www.reproductivefacts.org/globalassets/rf/news-and-publications/bookletsfact-sheets/english-fact-sheets-and-info-booklets/stress_and_infertility_factsheet.pdf

An, Y., Sun, Z., Li, L., Zhang, Y., & Ji, H. (2013). Relationship between psychological stress and reproductive outcome in women undergoing in vitro fertilization treatment: Psychological and neurohormonal assessment. *Journal of Assisted Reproductive Genetics, 30*(1), 35-41.doi:10.1007/s10815-012-9904-x

Annells, M. (1996). Hermeneutic phenomenology: Philosophical perspectives and current use in nursing research. *Journal of Advance Nursing, 23*(4), 705-713. doi:10.1111/j.1365-2648.1996.tb00041.x

Andrews, F.M., Abbey, A., & Halman, L.J. (1992). Is fertility-problem stress different? The dynamics of stress in fertile and infertile couples. *Fertility and Sterility, 57*(6), 1247-1253. doi: 10.1016/S0015-0282(16)55082-1

Andrews, I. (2010). Secondary infertility and birth mothers. *Psychoanalytic Inquiry, 30*(1), 80-93. doi:10.1080/07351690903200184

Appleton, J.V. (1995) Analyzing qualitative interview data: Addressing issues of validity and reliability. *Journal of Advanced Nursing, 22*(3), 993-997.

Armstrong, A., & Plowden, T.C. (2013). Ethnicity and assisted reproductive technologies. *Clinical Practice, 9*(6), 651-658. doi:10.2217/cpr.12.65

Ashing-Giwa, K.T., Padilla, G., Tejero, J. Kraemer, J., Wright, K., Coscarelli, A., Clayton, S., Williams, I., & Hills, D. (2004). Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina and White cancer survivors. *Psycho-Oncology, 13*, 408-428. doi:10.1002/pon.750

Awartani, K.A., Nahas, D., Al Hassan, S.H., Al Deery, M.A., & Coskun, S. (2009). Infertility treatment outcome in sub groups of obese population. *Reproductive Biology and Endocrinology, 7*(52), 1-5. doi:10.1186/1477-7827-7-52.

Bailey, C.A. (1996). *A guide to field research*. Thousand Oaks, CA: Pine Forge Press.

Balasch, J., & Gratacos, E. (2011). Delayed childbearing: Effects on fertility and the outcome pregnancy. *Fetal Diagnosis and Therapy, 29*(4), 263-273. doi:10.1159/000323142

Batool, S.S., & de Visser, R.O. (2016). Experiences of infertility in British and Pakistani Women: A cross-cultural qualitative analysis. *Health Care for Women International, 37*, 180-196. doi:10.1080/07399332.2014.980890

Beckes, L., & Coan, J. (2011). Social Baseline Theory: The role of social proximity in emotion and economy of action. *Social and Personality Psychology Compass, 5*, 976-988. doi:10.1111.J.1751-9004.2011.00400

Belle D. (1982). Social ties and social support. In D. Belle (Ed.), *Lives in stress: Women and depression* (pp. 133-144). Beverly Hills, CA: Sage Publications.

Belle D. (1983). The impact of poverty on social networks and supports. *Marriage & Family Review, 5*, 89-103. doi:10.1300/J002v05n04_06

Belsey, M.A. (1976). The epidemiology of infertility: a review with particular reference to sub-Saharan Africa. Bulletin of the World Health Organization, 54 (3),319-341.

Bentz, V.M., & Shapiro, J.J. (1998). *Mindful inquiry in social research*. Thousand Oaks, CA: Sage.

Benyamini Y., Gozlan M., & Kokia, E. (2005). Variability in the difficulties experienced by women undergoing infertility treatments. *Fertility and Sterility, 83*(2), 275–283. doi:10.1016/j.fertnstert.2004.10.014

Berkman L.F., & Glass T. (2000). Social integration, social networks, social support, and health. In L.F. Berkman & I. Kawachi (Eds.), *Social epidemiology* (pp. 158-162). New York: Oxford University Press.

Bitler, M., & Schmidt, L. (2006). Health disparities and infertility: Impacts of state-level insurance mandates. *Fertility and Sterility 85*(4), 858-865. doi:10.1016/j.fertnstert.2005.11.038.

Boss, P., Dahl, C., & Kaplan, L. (1996). The use of phenomenology for family therapy research: The search for meaning. In D.H. Sprenkle & S.M. Moon (Eds.), *Research methods in family therapy* (pp. 83-108) New York: Guilford.

Bolumar, F., Olsen, J., & Boldsen, J. (1996). Smoking reduces fecundity: A European Multicenter study on infertility and subfecundity. *American Journal of Epidemiology, 143*(6) 578-587. doi:10.1093/oxfordjournals.aje.a008788

Boulet, S.L., Crawford, S., Zhang, Y., Sunderam, S. Cohen, B., Bernson, D., McKane, P., Bailey, M.A., Jamieson, D.J., & Kissin, D.M. (2015). Embryo transfer practices and perinatal outcomes by insurance mandate status. *Fertility and Sterility, 104*(2), 403-409. doi:10.1016/j.fertnstert.2015.05.015

Bower, J.K., Schreiner, P.J., Sternfeld, B., & Lewis, C.E. (2009). Black-White differences in hysterectomy prevalence: The CARDIA Study. *American Journal of Public Health, 99*(2), 300-307. doi:10.2105/AJPH.2008.133702

Brach, C., & Fraserirector, I. (2000). Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review, 57*(1), 181-217. doi:10.1177/1077558700057001S09

Brandes, M., Van Der Steen, J.O.M., Bokdam, S.B., Hamilton, C.J.C.M., de Bruin, J.P., Nelen, W.L.D.M., & Kremer, J.A.M. (2009). When and why do subfertile couples discontinue their fertility care? A longitudinal cohort study in a secondary care subfertility population. *Human Reproduction, 24*(12), 3127-3135. doi:10.1093/humrep/dep340

Bristow, R.E., Chang, J., Ziogas, A., Campos, B., Chavez, L.R., & Anton-Culver, H. (2015). Sociodemographic disparities in advanced ovarian cancer survival and adherence to treatment guidelines. *Obstetrics and Gynecology, 125*(4), 833-842. doi:10.1097/AOG.0000000000000643

Brown, G., Marshall, M., Bower, P., Woodham, A., & Waheed, W. (2014). Barriers to recruiting ethnic minorities to mental health research: A systematic review. *International Journal of Methods in Psychiatric Research, 23*(1), 36-48.

doi:10.1002/mpr.1434

Brown, T.N., Williams, D.R., Jackson, J.S., Neighbors, H. W., Torres, M., Sellers, S. L., & Brown, K.T. (2000). “Being Black and feeling blue”: The mental health consequences of racial discrimination. *Race and Society, 2*, 117–131. doi:10.1016/S1090-9524(00)00010-3

Bulletti, C., Ziegler, D., Levi Setti, P., Cicinelli, E., Polli, V., & Stefanetti, M. (2004). Myomas, pregnancy outcome, and in vitro fertilization. *Annals of New York Academy of Science*, *1034*(1),84–92. doi:10.1196/annals.1335.010

Burgess, D., van Ryn, M., Dovidio, J., & Saha, S. (2007). Reducing racial bias among health care providers: Lesson from social-cognitive psychology. *Society of General Internal Medicine, 22*, 882-887. doi:10.1007/s11606-007-0160-1

Burnard, P. (1991). A method of analyzing interview transcripts in qualitative research. *Nurse Education Today, 11*, 461-466.

Campo, S., Campo, V., & Benagiano, G. (2012). Adenomyosis and infertility. *Reproductive BioMedicine Online, 24*(1), 35-46. doi:10.1016/j.rbmo.2011.10.003

Carey, J.W., Morgan, M., & Oxtoby, M.J. (1996). Intercoder agreement in analysis of responses to open-ended interview questions: Examples from tuberculosis research. *Journal of Cultural Anthropology Methods, 8*(3), 1-5.

Cary, L. (1992). Why it’s not just paranoia: An American history of “plans” for blacks. *Newsweek, 69*(14), 23.

Cavanagh S. (1997). Content analysis: Concepts, methods and applications. *Nurse Researcher 4*(3), 5-16. doi:10.7748/nr.4.3.5.s2

Cayan, S., Shavakhabov, S., & Kadioglu, A. (2009). Treatment of palpable varicocele in infertile men: A meta-analysis to define the best technique. *Journal of Andrology, 30*(1), 33-40. doi:10.2164/jandrol.108.005967

Chandra, A. Copen, C.E., & Stephen, E.H. (2013). Infertility and impaired fecundity in the United States 1982-2010: Data from The National Survey of Family Growth, *National Health Statistics Reports, 67*, 1-18.

Chandra, A., Copen, C.E. & Stephen, E.H. (2014). Infertility service use in the United States: Data from the National Survey of Family Growth, 1982-2010. *National Health Statistics Reports, 73*, 1-20.

Chandra, A., & Stephen, E.H. (2006). Declining estimates of infertility in the United States: 1982-2002. *Fertility and Sterility, 86*(3), 516-523. doi:10.1016/j.fertnstert.2006.02.129

Chandra, A., & Stephen, E.H. (2010). Infertility service use among U.S. women: 1995 and 2002. *Fertility and Sterility, 93*(3),725–736. doi:10.1016/j.fertnstert.2008.10.049

Chandler, R.F., & Monnat, S.M. (2015). Racial/ethnic differences in use of health care services for diabetes management, *42*(6), 783-792. doi:10.1177/1090198115579416

Chatterjee, S., Gupta, D., Caputo, T.A., & Holcomb, K. (2016). Disparities in gynecological malignancies. *Frontiers in Oncology, 6*(36), 1-4 doi:10.3389/Fonc.2016.00036

Chen, C., Buck, G.M., Courey, N. G., Perez, K.M., & Wactawski-Wende, J. (2001). Risk factors for uterine fibroids among women undergoing tubal sterilization. *American Journal of Epidemiology, 153*(1), 20-26. doi:10.1093/aje/153.1.20

Chow, E.T., & Mahalingaiah, S. (2016). Clinical vignettes and global health considerations of infertility care in under-resourced patients. *Fertility Research and Practice, 2*(1), 4. doi:10.1186/s40738-016-0017-6

Clark, E. (2000). The historical context of research in midwifery. In S. Proctor and M. Renfrew (Eds.), *Linking research and practice in midwifery: A guide to evidence-based practice* (pp. 35-54). Edinburgh: Bailliere Tindal.

Cohen, S., & Willis T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310-357. doi: 10.1037/0033-2909.98.2.310

Cook, H., Ezzati, M., Segars, J.H., & McCarthy, K. (2010). The impact of uterine leiomyomas on reproductive outcomes. *Minerva Ginecologica, 62*(3), 225-236.

Cooke, A., Mills, T.A., & Lavender, T. (2012). Advanced maternal age: Delayed childbearing is rarely a conscious choice a qualitative study of women's views and experiences. *International Journal of Nursing Studies, 49*(1), 30-39. doi:10.1016/j.ijnurstu.2011.07.013

Copeland, V.C., & Snyder, K. (2011). Barriers to mental health treatment services for low income African American women whose children receive behavioral health services: An ethnographic investigation. *Social Work in Public Health, 26*(1), 78–95. doi:10.1080/ 10911350903341036

Costello, C.G. (1982) Social factors associated with depression: A retrospective community study. *Psychological Medicine 12*(2), 329-339.

doi:10.1017/S0033291700046663

Creswell, J.W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd Ed.) Thousand Oaks, CA: Sage.

Culley, L.A., Hudson, N., & Van Rooij, F. (2009). Introduction: Ethnicity, infertility and assisted reproductive technologies. In L. Culley, N. Hudson, & F. Van Rooij (Eds), *Marginalized reproduction: Ethnicity, infertility and reproductive technologies* (pp. 1-14). London: Earthscan.

Cutcliffe, J.R., & McKenna, H.P. (1999). Establishing the credibility of qualitative research finding: The plot thickens. *Journal of Advance Nursing, 30*(2), 374-380. doi: 10.1046/j.1365-2648.1999.01090.x

Darawsheh, W. (2014). Reflexivity in research: Promoting rigor, reliability and validity in qualitative research. *International Journal of Therapy and Rehabilitation, 21*(12), 560-568. doi:10.12968/ijtr.2014.21.12.560

Davies, M.B. (2007). *Doing a successful research project: Using qualitative or quantitative methods*. Basingstoke [England]: Palgrave MacMillian.

Davis, C.H., III, Hall, M.N., & Kaufmann, L. (2007). What is the best way to evaluate secondary infertility? *The Journal of Family Practice, 56*(7), 573-575.

DeNavas-Walt C., Proctor, B.D., & Smith J. (2007). *Income, poverty, and health insurance coverage in the United States: 2006*. U.S. Census Bureau Current Population Reports, P60-233. Washington, DC: U.S. Government Printing Office. Retrieved from https://www.census.gov/prod/2007pubs/p60-233.pdf

DeSantis, C.E., Siegel, R.L., Sauer, A., Miller, K. D., Fedewa, S.A., Alcaraz, K.L., &

Jemal, A. (2016). Cancer statistics for African American, 2016: Progress and opportunities in reducing racial disparities. *CA: A Cancer Journal for Clinicians, 66*, 290-308. doi.10.3322/Caac.21340

Devers, K.J., & Frankel, R.M. (2000). Study design in qualitative research-2: Sampling and data collection strategies. *Education for Health 13*(2), 263-271. doi: 10.1080/13576280050074543

Devine, K., Stillman, R.J., & DeCherney, A. (2014). The Affordable Care Act: Early implications for fertility medicine. *Fertility and Sterility, 101*(5), 1224-1227. doi:10.1016/j.fertnstert.2014.01.024

Durant, R.W., Davis, R.B., St George, D.M., Williams, I.C., Blumenthal, C., & Corbie-Smith, G.M. (2007). Participation in research studies: Factors associated with failing to meet minority recruitment goals. *Annals of Epidemiology, 17*(8), 634-642. doi:10.1016/j.annepidem.2007.02.003

Dutton, D.B., & Levine S. (1989). Overview, methodological critique, and reformulation. In J.P. Bunker, D.S. Gomby, & B.H. Kehrer (Eds.), *Pathways to health: The role of social factors* (pp. 29-69). Menlo Park, CA: Henry J. Kaiser Family Foundation

Edin, K., & Lein, L. (1997). Survival strategies. In *Making ends meet: How single mothers survive welfare and low-wage work* (pp. 143-191). New York: Russell Sage Foundation.

Ejiogu, N., Norbeck, J.H., Mason, M.A., Cromwell, B.C., Zonderman, A.B., & Evans. M.K. (2011). Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the Healthy Aging in Neighborhoods of

Diversity across the Life Span Study. *The Gerontologist, 51*, 533-545. doi:10.1093/geront/gnr027

Eltoukhi, H.M., Modi, M.N., Weston, M., Armstrong, A., & Stewart, E.A. (2014). The health disparities of uterine fibroid tumors for African American women: A public health issue. *American Journal of Obstetrics and Gynecology, 210*(3),194-199. doi:10.1016/j.ajog.2013.08.008

Epstein, Y.M., & Rosenberg, H.S. (2005). Depression in primary versus secondary infertility egg recipients. *Fertility and Sterility, 83*(6), 1882-1884. doi:10.1016/j.fertnstert.2005.01.098.

Feinberg, E.C., Larsen, F.W., Catherino, W.H., Zhang, J., & Armstrong, A.Y. (2006). Comparison of assisted reproductive technology utilization and outcomes between Caucasian and African American patients in an equal-access-to-care setting. *Fertility and Sterility 85*(4), 888-894. doi: 10.1016/j.fertnstert.2005.10.028

Fekkes, M., Buitendijk, S.E., Verrips, G.H.W., Braat, D.D.M., Brewaeys, A.M.A., Dolfing, J.G., Kortman, M., Leerentveld, R.A., & Macklon, N.S. (2003). Health-related quality of life in relation to gender and age in couples planning IVF treatment. *Human Reproduction, 18*(7), 1536–1543. doi:10.1093/humrep/deg276

Galhardo, A., Pinto-Gouveia, J., Cunha, M., & Matos, M. (2011). The impact of shame and self-judgment on psychopathology in infertile patients. *Human Reproduction, 26*, 2408-2414. doi:10.1093/humrep/der209

Galletta, A. (2012). Mastering the semi-structured interview and beyond: From research design to analysis and publication. New York: New York University Press.

Gamble, V.N. (1997) Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health, 87*, 1773-1778. doi:10.2105/AJPH.87.11.1773

Gaur, D.S., Talekar, M.S., & Pathak, V.P. (2010). Alcohol intake and cigarette smoking: Impact of two major lifestyle factors on male fertility. *Indian Journal of Pathology and Microbiology, 53*(1), 35-40. doi:10.4103/0377-4929.59180

Geer, J.G. (1988). What do open-ended questions measure? *The Public Opinion Quarterly, 52*(3), 365-367. doi: 10.1086/269113

Gilbert, D. (2003). *The American class structure in an age of growing inequality.* 6th ed. Belmont, CA: Wadsworth.

Giorgi, A. (1985). Sketch of a psychological phenomenological method. In A. Giorgi (Ed.), *Phenomenology and psychological research* (pp. 8-22). Pittsburgh, PA: Duquesne University Press.

Gnoth, C., Godehardt, E., Frank-Herrmann, P., Friol, K., & Freundl, G. (2005). Definition and prevalence of subfertility and infertility. *Human Reproduction, 20*(5), 1144-1147. doi:10.1093/humrep/deh870

Goerke, H. (1956). The life and scientific works of Dr. John Quier, practitioner of physic and surgery; Jamaica: 1738-1822. *West Indian Medical Journal, 5*(1), 23-27.

Goff, B.A., Mathews, B.J., Larson, E.H., Andrilla, C.H.A., Wynn, M., Lishner, D.M., & Baldwin, L. (2007). Predictors of comprehensive surgical treatment in patients with ovarian cancer. *Cancer, 109*, 2031-2042. doi:10.1002/Cncr.22604

Gorelick, J.I., & Goldstein, M. (1993). Loss of fertility in men with varicocele. *Fertility and Sterility, 59*(3), 613-616. doi:10.1016/S0015-0282(16)55809-9

Goza, F.W., Stockwell, E.G., & Balistreri, K.S. (2007). Racial differences in the relationship between infant mortality and socioeconomic status. *Journal of Biosocial Science. 39*, 517-529. doi:10.1017/S0021932006001581

Graziano, A., Lo Monte, G., Piva, I., Caserta, D., Karner, M., Engl, B., & Marci, R. (2015). Diagnostic findings in adenomyosis: A pictorial review on the major concerns. *European Review for Medical and Pharmacological Sciences 19*, 1146-1154.

Greil, A.L. (1997). Infertility and psychological distress: A critical review of the literature. *Social Science and Medicine, 45*, 1697-1704. doi: 10.1016/S0277-9536(97)00102-0

Greil, A.L., McQuillan, J., & Sanchez, D. (2016). Does fertility-specific distress vary by race/ethnicity among a probability sample of women in the United States. Journal of Health Psychology, 21(2)183-192. doi: 10.1177/1359105314524970

Greil, A.L., McQuillan, J., Lowry, M., & Shreffler, K.M. (2011). Infertility treatment and fertility-specific distress: A longitudinal analysis of a population-based sample of U.S. women. *Journal of Social Science Medicine, 73*(1), 87-94. doi:10.1016/J.Socscimed.2011.04.023

Greil, A.L., Slauson-Blevins, K., & McQuillan, J. (2010). The experience of infertility: A review of recent literature. *Sociology of Health & Illness, 32*(1),140-162. doi:10.1111/J.1467-9566.2009.01213.X

Guba, E.G., & Lincoln, Y.S. (1981). *Effective evaluation: Improving the usefulness of evaluation results through responsive and naturalistic approaches*. San Francisco: Jossey-Bass.

Gurunath, S., Pandian, S., Anderson, R.A., & Bhattacharya, S. (2011). Defining infertility—a systematic review of prevalence studies. *Human Reproduction Update, 17*(5), 575-588. doi:10.1093/humupd/dmr015

Hammersley, M. (1990). Reading ethnographic research: A critical guide. London: Longman.

Hao, L. (2004). Wealth of immigrant and native-born Americans. *International Migration Review, 38*(2), 518-546. doi:10.1111/j.1747-7379.2004.tb00208.x

Hasan, F., Arumugam, K., & Sivanesaratnam, V. (1990) Uterine leiomyomata in pregnancy. *International Journal of Gynecology and Obstetrics, 34*(1), 45–48. doi:10.1016/0020-7292(91)90537-F

Hassan, M.A.M., & Killick, S.T. (2004). Negative lifestyle is associated with significant reduction in fecundity. *Fertility and Sterility, 81*(2), 384-392. doi:10.1016/j.fertnstert.2003.06.027

Hatch, L.R. (1991). Informal support patterns of older African American and white women: Examining effects of family, paid work and religious participation. *Research on Aging, 13*(2), 144-170. doi:10.1177/0164027591132003

Hayon. R., Dalby, J., Paddock, E., Combs, M., & Schrager, S. (2013). Reproductive health care of adolescent women. *Journal of the American Board of Family Medicine, 26*(4), 460-468. doi:10.3122/jabfm.2013.04.120283

Hazel, E., Conrad, L., & Martin, E. (1997). Exploring gender and phenomenography. *Higher Education Research and Development, 16*(2), 213–226. doi:10.1080/0729436970160208

Heaney C.A., & Israel B.A. (2001). Social networks and social support. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), *Health behavior and health education: Theory, research, and practice* (2nd ed., pp. 185-209). San Francisco: Jossey-Bass.

Hibbard, J.H., Greens, J. Becker, E.R, Robin, D., Painter, M.W., Perez, J., Burbank-Schmitt, E., & Tusler, M. (2008). Racial/ethnic disparities and consumer activation in health. *Health Affairs, 27*(5), 1442-1453. doi:10.1377/Hlthaff.27.5.1442

Hood, R. (2016). Combining Phenomenological and critical methodologies in qualitative research. *Qualitative Social Work, 15*(2), 160-174. doi:10.1177/1473325015586248

House, J.S. (1981). *Work stress and social support*. Reading, MA: Addison-Wesley.

Humphrey, D.C. (1973). Dissection and discrimination: The social origins of cadavers in American, 1760-1915. *Bulletin of the New York Academy of Medicine, 49*(9), 819-827.

Huyck, K.L., Panhuysen, M.L., Cuenco, K.T., Jingmei, Z., Goldhammer, H., Jones, E.S., Somasundaram, P., Lynch, A.M., Harlow, B.L., Lee, H., Stewart, E.A., & Morton, C.C. (2008). The impact of race as a risk factor symptom severity and age at diagnosis of uterine leiomyomata among affected sisters. *American Journal of Obstetrics and Gynecology, 198*, 168.e1-168.e9.

doi:10.1016/j.ajog.2007.05.038

Irvine, S.D.(1998). Epidemiology and aetiology of male infertility. *Human Reproduction, 13 (*1), 33-44. doi:10.1093/humrep/13.suppl_1.33

Israel, B.A. (1985). Social networks and social support: Implications for natural helper and community level interventions. *Health Education Quarterly, 12*(1), 65-80. doi:10.1177/109019818501200106

Jain, T. (2006). Socioeconomic and racial disparities among infertility patients seeking care. *Journal of Fertility and Sterility, 85*, 876–881. doi:10.1016/j.fertnstert.2005.07.1338

Jain, T., & Hornstein, M.D. (2005). Disparities in access to infertility services in State with mandated insurance coverage. *Fertility Sterilization, 84*(1), 221-223. doi:10.1016/j.fertnstert.2005.01.118

Jarrow, J., Sigman, M., Kolettis, P., Lipshultz, L.R., McClure, R.D., Nangia, A.K., Naughton, C.K., Prins, G.S., Sandlow, J.I., & Schlegel, P.N. (2011). *Male infertility: The optimal evaluation of the infertile male: Best practice statement. Reviewed and validity confirmed.* American Urological Association. Retrieved on November 23, 2016 from http://tinyurl.com/hce3o4y

Johnson, M.L. (1995). Interdependency and the generational compact. *Aging and Society, 15*, 243-265. doi:10.1017/S0144686X00002397

Jones, C.A., Gray, L., & Lui, K. (2012). Fertility treatment decision-making: The effect of insurance coverage for fertility medications. *Journal of Obstetrics and Gynaecology Canada, 34*(11), 1066-1072. doi:10.1016/S1701-2163(16)35436-6

Jungheim, E. (2015). A validated prediction model for IVF: Is it clinically applicable? *American Journal of Obstetrics & Gynecology 212*(5), 556–558. doi:10.1016/j.ajog.2015.03.028

Jungwirth, A., Diemer, T., Dohle., G.R. Giwercman, A., Kopa, Z., Krausz, C., & Tournaye, H. (2015). *Guidelines on male infertility*. European Association of Urology, the Netherlands. Retrieved on November 23, 2016 from http://tinyurl.com/ hgrtkka.

Kabat-Zinn, J. (2012). *Mindfulness for beginners*. Boulder, CO: Sounds True, Inc.

Kallio, H., Pietila, A., Johnson, M., & Docent, M.K. (2016). Systematic methodological review: Developing a framework for qualitative semi-structured interview guide. *Journal of Advanced Nursing, 72*(12), 2954-2965. doi:10.1111/jan.13031

Kessler, L.M., Craig, B.M., Plosker, S.M., Reed, D.R., & Quinn, G.P. (2013). Infertility evaluation and treatment among women in the United States. *Fertility and Sterility, 100*(4), 1025-32. doi:10.1016/j.fertnstert.2013.05.040

Khan, S.J., Gulab, N., & Khan, P.J. (2014). Frequency of pelvic inflammatory disease among women presenting with infertility. *Khyber Journal of Medical Science, 7*(1), 138-141.

Kim, J., Oktay, K., Garcia, C., Lee, S., Morse, C., & Mersereau, J.E. (2012). Which patients pursue fertility preservation treatments? A multicenter analysis of the predictors of fertility preservation in women with breast cancer. *Fertility and Sterility, 97*(3), 671-676. doi:10.1016/j.fertnstert.2011.12.008

Kim, Y. (2010). The pilot study in qualitative inquiry: Identifying issues and learning lessons for culturally competent research. *Qualitative Social Work, 10*(2),190-206. doi:10.1177/1473325010362001

King, N. (1994). The qualitative research interview. In C. Cassell & G. Symon (Eds.), Qualitative methods in organizational research: A practical guide (pp. 14-36). Thousand Oaks, CA, US: Sage Publications, Inc.

Kjerulff, K.H. Velott, D.L., Zhu, J., Chuang, C.H., Hillemeier, M.M., Paul, I.M., & Repke, J.T. (2013). Mode of first delivery and women's intentions for subsequent childbearing: Findings from the First Baby Study. *Paediatric and Perinatal Epidemiology, 27*, 62-71. doi:10.1111/Ppe.12014

Klein, S.M., & Garcia, C.R. (1973). Asherman's Syndrome: A critique and current review. *Fertility and Sterility, 24*(9), 722-735. doi:10.1016/S0015-0282(16)39918-6

Koepke, D. (2007). Race, class, poverty and capitalism. *Race, Gender & Class 14*(3/4), 189-205.

Lagana, A.S., Vitale, S.G., Laconianni, P., Gatti, S., & Padula, F. (2016). Male infertility during antihypertensive therapy: Are we addressing correctly the problem? *International Journal of Fertility and Sterility, 10*(3), 267-269. doi:10.22074/ijfs.2016.4633

Lai, G. Y., Gary, T. L., Tilburt, J., Bolen, S., Baffi, C., Wilson, R. F., Howerton, M.W., Gibbons, M.C., Tanpitukpongse, T.P., Powe, N.R., Bass, E.B., & Ford, J.G. (2006). Effectiveness of strategies to recruit underrepresented populations into cancer clinical trials. *Clinical Trials, 3*(2), 133-141.

doi:10.1191/1740774506cn143oa.

Landrine, H., & Klonoff, E.A., (1994). Cultural diversity in causal attributes for illness: The role of the supernatural. *Journal of Behavioral Medicine, 17*, 181-193. doi: 10.1007/BF01858104

Larsen, U. (1994). Sterility in Sub-Saharan Africa. *Population Studies, 48*,459- 474. doi:10.1080/0032472031000147976

Larsen, U. (2000). Primary and secondary infertility in sub-Saharan Africa. *International Journal of Epidemiology, 29*(2), 285-291. doi:10.1093/Ije/29.2.285

Larsen, U. (2005). Research on infertility: Which definition should we use? *Fertility and Sterility, 83*(4) 846-852. doi:10.1016/J.Fertnstert.2004.11.033

Lee, G.L., Hui Choi, W.H., Chan, C.H.Y., Chan, C.L.W. & Ng, E.H.Y. (2009). Life after unsuccessful IVF treatment in an assisted reproductive unit: A qualitative analysis of gains through loss among Chinese persons in Hong Kong. *Human Reproduction 24*(8), 1920-1929. doi:10.1093/humrep/dep091

Levine, D.S., Taylor, R.J., Nguyen, A.W., Chatters, L.M., & Himle, J.A. (2015). Family and friendship informal support networks and social anxiety disorder among African American and Black Caribbean. *Social Psychiatry and Psychiatric Epidemiology, 50*(7), 1121-1133. doi:10.1007/S00127-015-1023-4

Li, X., Liu, X., & Guo, S. (2014). Clinical profiles of 710 premenopausal women with adenomyosis who underwent hysterectomy. *Journal of Obstetrics and Gynaecology Research, 40*(2), 485-494. doi:10.1111/jog.12211

Lok, I. H., Lee D. T., Cheung L .P., Chung W.S., Lo W.K., & Haines C. J. (2002).

Psychiatric morbidity amongst infertile Chinese women undergoing treatment with assisted reproductive technology and the impact of treatment failure. *Gynecologic and Obstetric Investigation, 53*(4), 195–199. doi:10.1159/000064560

Lowyck, B., Luyten P., Corveleyn, J., D'Hooghe, T., Buyse, E., & Demyttenaere, K. (2009). Well-being and relationship satisfaction of couples dealing with an in vitro fertilization/intracytoplasmic sperm injection procedure: A multilevel approach on the role of self-criticism, dependency, and romantic attachment. *Fertility and Sterility, 91*(12), 387–394. doi:10.1016/j.fertnstert.2007.11.052

Magasi, S., & Hammel, J. (2004). Social support and social network mobilization in older African American women who have experienced strokes. *Disability Studies Quarterly. 24*(4). Retrieved on October 26, 2016 from http://www.dsq-sds.org/article/view/878/1053

Mammo, A., & Morgan, S.P. (1986). Childlessness in rural Ethiopia*. Population and Development Review, 12*(3), 533-546. doi: 10.2307/1973223

Mascarenhas, M.N., Flaxman, S.R., Boerma, T., Vanderpoel, S., & Stevens, G. (2012). National, regional, and global trends in infertility prevalence since1990: A systematic analysis of 277 health surveys. *PLoS Medicine, 9*(12), 1-12. doi:10.1371/journal.pmed.1001356

Mascarenhas, M.N., Hoiwan, C., Mathers, C.D., & Stevens, G.A. (2012). Measuring infertility in populations: Constructing a standard definition for use with demographic and reproductive health surveys. *Population Health Metrics, 10*(17), 1-11. doi:10.1186/1478-7954-10-17

Matthews, T.J., & Hamilton, B.E. (2009). Delayed childbearing: More women are having their first child later in life. *National Center for Health Statistics Data Brief 21*, 1-8.

McPhail, J.C. (1995). Phenomenology as philosophy and method: Applications to ways of doing special education. *Remedial and Special Education, 16*(3), 159-165. doi: 10.1177/074193259501600305

Mills, T.A., & Lavender, T. (2011). Advanced maternal age. *Obstetrics, Gynaecology & Reproductive Medicine, 21*(4), 107-111. doi:10.1016/j.ogrm.2010.12.003

Misser, S. A., Seifer, D. B., & Jain, T. (2011). Cultural factors contributing to health care disparities among patients with infertility in Midwestern United States. *Fertility and Sterility, 95*(6), 1943-1949. doi:10.1016/j.fertnstert.2011.02.039

Mogobe, D. K. (2005). Denying and preserving self; Batswana women's experiences of infertility. *African Journal of Reproductive Health, 9*, 26-37. doi:10.2307/3583460

Monnet, S. M. (2014). Race/ethnicity and the socioeconomic status gradient in women's cancer screening utilization: A case of diminishing returns? *Journal of Health Care for the Poor and Underserved, 25*(1), 332-356. doi:10.1353/Hpu.2014.0050

Moore, C., Boyd, B.L., & Dooley, K.E. (2010). The effects of experiential learning with an emphasis on reflective writing on deep-level processing of leadership students. *Journal of Leadership Education, 9*, 36–52.

Morgan, S.P., & Hagewen, K. (2005). Is very low fertility inevitable in America? Insights and forecasts from an integrative model of fertility. In A. Booth, A.C.

Crouter (Eds.), *The new population problem; Why families in developed countries are shrinking and what it means* (pp. 3-28). Mahwah, NJ: Lawrence Erlbaum.

Mosalanejad, L, Parandavar, N., Gholami, M., & Addollahifard, S. (2014). Increasing and decreasing factors of hope in infertile women with failure in infertility treatment: A phenomenology study. *Iran Journal of Reproductive Medicine. 12*(2), 117-124.

Moura-Ramos, M., Gameiro, S., Canavarro, M.C., Soares, I., & Almeida-Santos, T. (2016). Does infertility history affect the emotional adjustment of couples undergoing assisted reproduction? The mediating role of the importance of parenthood. *British Journal of Health Psychology, 21*(2), 302-317. doi:10.1111/Bjhp.12169

Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.

Mundigo, A.I. (1998). The role of men in improving reproductive health: The direction research should take. In J. Khanna & P.F.A. Van Look (Eds.), *Reproductive Health Research: The New Directions, Biennial report 1996-1997*. Geneva, Switzerland: World Health Organization.

Nachtigall, R.D. (2005). International disparities in access to infertility services. *Fertility and Sterility, 8*(4), 871-875. doi:10.1016/J.Fertnstert.2005.08.066

Nasser, N., Gardy, D., & Balke, C.W. (2011). Commentary: Improving participant recruitment in clinical and translational research. *Academic Medicine, 86*(11), 1334-1335. doi:10.1097/ACM.0b013e3182302831

National Institute for Health Care Excellence [NICE]. (2013) *Fertility: Assessment and* *treatment for people with fertility problems*. London: Author.

Navarro, V. (1990). Race or class versus race and class: Mortality differentials in the United States. *Lancet, 336*(8725), 1238-1240.

Neff, K.D. (2008). Self-compassion: Moving beyond the pitfalls of a separate self-concept. In J. Bauer & H.A. Wayment (Eds.), *Transcending self-interest: Psychological explorations of the quiet ego* (pp. 95–106). Washington, DC: American Psychological Association.

Obeidat, H.M., Hamlan, A.M., & Clark-Callister, L. (2014). Missing motherhood: Jordanian women's experiences with infertility. *Advances in Psychiatry, 2014*, 1-7. doi:10.1155/2014/241075

Odafe, M.O., Salami, T.K., & Walker, R.L. (2017). Race-related stress and hopelessness in community-based African American adults: Moderating role of social support. *Cultural Diversity and Ethnic Minority Psychology, 23*(4), 561-569. doi:10.1037/cdp0000167

Opdenakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research. *Forum: Qualitative Social Research, 7*(4), 1-13. doi:10.17169/fqs-7.4.175

Padgett, D.K. (2008) *Qualitative methods in social work research*, 2nd ed. Los Angeles, CA: SAGE.

Painter, M.A., II (2013). Immigrant and native financial well-being: The roles of place of education and race/ethnicity. *Social Science Research, 42*(5), 1375–1389. doi:10.1016/j.ssresearch.2013.04.001

Parahoo, K. (2006) *Nursing research principles, process and issues* (2nd ed.). Basingstoke: Palgrave McMillan.

Patton, M.Q. (1999). Enhancing the quality of credibility of qualitative analysis. *Health Services Research, 34*(5 PT2), 1189-1208.

Peterson, B.D., Pirritano, M., Christensen, U., Boivin, J., Block, J., & Schmidt, L. (2009). The longitudinal impact of partner coping in couples following 5 years of unsuccessful fertility treatment. *Human Reproduction, 24*(7), 1656-1664. doi:10.1093/Humrep/Dep061

Peterson, B.D., Pirritano, M., Christensen, U., & Schmidt, L. (2008). The impact of partner coping in couples experiencing infertility. *Human Reproduction, 23*(5), 1128-1137. doi:10.1093/Humrep/Den067

Pfeil, M., & Lindsay, B. (2010). Hypospadias repair: An overview. *International Journal of Urological Nursing, 4*(1), 4-12. doi:10.1111/j.1749-771X.2010.01074.x

Poppe, K., Velkeniers, B., & Glinoer, D. (2007). Thyroid disease and female reproduction. *Clinical Endocrinology, 66*(3), 309-321. doi:10.1111/j.1365.2265.2007.02752.x

Pottinger, A.M., McKenzie, C., Fredericks, J., Dacosta, V., Wynter, S., Everett, D., & Walters, Y. (2006). Gender differences in coping with infertility among couples undergoing counselling for *in vitro* fertilization treatment. *West Indian Medical Journal, 55*(4), 237-242.

Quach, S., & Librach, C. (2008). Infertility knowledge and attitudes in urban high school students. *Fertility and Sterility, 90*(6), 2099-2106.

doi:10.1016/J.Fertnstert.2007.10.024

Quant, H.S., Zapantis, A., Nihsen, M., Bevilacqua, K., Jindal, S., & Pal, L. (2013). Reproductive implications of psychological distress for couples undergoing IVF. *Journal of Assisted Reproduction and Genetics, 30*(11), 1451-1458. doi:10.1007/S10815-013-0098-7

Rafaeli, E., & Gleason, M. E. J. (2009). Skilled support within intimate relationships. *Journal of Family Theory and Review, 1*, 20–37. doi:10.1111/J.1756-2589.2009.00003.X

Raque-Bogdan, T.L. & Hoffman, M., (2015) The relationship among infertility, self compassion and wellbeing for women with primary care and secondary infertility. *Psychology of Women Quarterly, 39*(4) 484-496. doi:10.1177/0361684315576208

Rejeski, W.J., Fielding, R.A., Blair, S.N., Guralnik, J.M., Gill, T.M., Hadley, E.C., King, A.C., Kritchevsky, S.B., Miller, M.E., Newman, A.B., & Pahor, M. (2005). The lifestyle interventions and independence for elders (LIFE) pilot study: Design and methods. *Contemporary Clinical Trials, 26*(2), 141 -154. doi:10.1016/j.cct.2004.12.005

Revonta, M., Raitanen, J., Sihvo, S., Kopenen, P., Klemetti, R., Mannisto, S., & Luoto, R. (2010). Health and life style among infertile men and women. *Sexual & Reproductive Healthcare, 1*(3), 91-98. doi:10.1016/j.srhc.2010.06.002

Roberts, T. (2013). Understanding the research methodology of interpretative phenomenological analysis. *British Journal of Midwifery, 21*(3), 215-218.

Robinson, O.C. (2014) Sampling in interview-based qualitative research: A theoretical and practical guide.. *Qualitative Research in Psychology, 11*(1), 25-41. doi:10.1080/14780887.2013.801543

Robinson, O.C., & Smith, J.A. (2010). Investigating the form and dynamics of crisis episodes in early adulthood: The application of a composite qualitative method. *Qualitative Research in Psychology, 7*(2), 170–191. doi:10.1080/14780880802699084

Rolfe, G. (2006). Validity, trustworthiness and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing, 53*(3), 304-310. doi:10.1111/j.1365-2648.2006.03727.x

ROuchou, B.(2013). Consequences of infertility in developing countries. *Perspectives in Public Health*, 133*(3),* 174-179. doi: 10.1177/1757913912472415

Rowland, D.T. (2007). Historical trends in childlessness. *Journal of Family Issues, 23*(10), 1311–37. doi:10.1177/0192513X07303823

Rudestam, K.E., & Newton, R.R. (2015). *Surviving your dissertation: A comprehensive guide to content and process.* (4th Ed.). Thousand Oaks, CA: Sage Publications.

Rutstein, S.O., & Shah, I.H. (2004). Infecundity, infertility, and childlessness in developing countries. DHS Comparative Reports No. 9. Calverton, Maryland, USA: ORC Macro and the World Health Organization.

Ryan, F., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research: The one-to-one interview. *International Journal of Therapy and Rehabilitation, 16*(6), 309-314. doi:10.12968/ijtr.2009.16.6.42433

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing and*

Health, 18(2), 179-183.

Savitt, T.L. (1982) The use of Blacks for medical experimentation and demonstration in the old south. *Journal of Southern History, 48*(3) 331-348. Retrieved on January 11, 2017 from http://www.jstor.org/stable/2207450. doi:10.2307/2207450

Schiebinger, L. (2004). *Plants and empire: Colonial bioprospecting in the Atlantic World*. Cambridge, MA: Harvard University Press.

Schiebinger, L. (2017). *Secret cures of slaves: People, plants, and medicine in the eighteenth-century Atlantic World*. Stanford, CA: Stanford University Press.

Schmidt, L.(2009). Social and psychological consequences of infertility and assisted reproduction--what are the research priorities? *Human Fertility, 12*(1), 14-20. doi:10.1080/14647270802331487

Schmidt, L., Holstein, B., Christensen, U., & Boivin, J. (2005). Does infertility cause marital benefit? An epidemiological study of 2250 women and men in fertility treatment. *Patient Education and Counseling, 59*(3), 244-251. doi:10.1016.J.Pec.2005.07.015

Schonfeld, I.S. (1991). Dimensions of functional social support and psychological symptoms. *Psychological Medicine, 21*, 1051–1060. doi:10.1017/S003329170003004X

Schulz, A., Williams, D., Israel, B., Becker, A., Parker, E., James, S.A., & Jackson, J. (2000). Unfair treatment, neighborhood effects, and mental health in the Detroit metropolitan area. *Journal of Health and Social Behavior, 41*, 314-332. doi:10.2307/2676323

Schulz, A.J., Parker, E.A., Israel, B.A., Allen, A., Decarlo, M., & Lockett, M. (2002). Addressing social determinants of health through community-based participatory research: The East Side Village Health Worker Partnership.. *Health Education & Behavior, 29*(3), 326-341. doi:10.1177/109019810202900305

Schwieter, J.W. (2011). Migrant Hispanic students speak up: Linguistic and cultural perspectives on low academic attainment. *Diaspora, Indigenous and Minority Education, 5*, 33-47. doi:10.1080/15595692.2011.534401

Sexual and Reproductive Health: Infertility definitions and terminology. World Health Organization. Retrieved on October 26, 2016 from Http://www.who.int/reproductivehealth/topics/infertility/definitions/En/

Sharara, F., & McClamrock, H.D. (2000). Differences in in vitro fertilization (IVF) outcomes between white and black women in an inner city, university-based IVF program. *Fertility and Sterility, 73*(6), 1170-1173. doi:10.1016/S0015-0282(00)00524-0

Sheridan, R. (1985). Doctors and slaves: A medical and demographic history of slavery in the British West Indies 1680 to 1834. New York: Cambridge University Press.

Sims, J.M. (1884). *The story of my life*. New York: Appleton.

Singh, K.K., Bloom, S., & Tusi, A.O. (1998) Husband's reproductive health knowledge, attitudes and behavior in Uttar Pradesh, India. *Studies in Family Planning, 29*(4), 388-399. doi:10.2307/172251

Smith, J.A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Wellbeing,* *2*(1), 3-11. doi:10.1080/17482620601016120

Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, methods and research*. London: Sage.

Smith, J.F., Eisenberg, M.L., Glidden, D., Millstein, S.G., Cedars, M., Walsh, T.J., Showstack, J., Pasch, L.A., Adler, N., & Katz, P.P. (2011). Socioeconomic disparities in the use and success of fertility treatments: Analysis of data from a prospective cohort in the United States. *Fertility and Sterility, 96*(1), 95-101. doi:10.1016/j.fertnstert.2011.04.054

Stolwijk, A.M, Wetzels, A.M., & Braat, D.D. (2000). Cumulative probability of achieving an ongoing pregnancy after in-vitro fertilization and intracytoplasmic sperm injection according to a woman's age, subfertility diagnosis and primary or secondary subfertility. *Human Reproduction, 15*(1), 203-209. doi:10.1093/humrep/15.1.203

Surkan, P.J., O'Donnell, E.M., Berkman, L.F., & Peterson, K. E. (2009). Social ties in relation to health status of low-income Brazilian women. *Journal of Women's Health, 18*, 2049-2056. doi:10.1089/jwh.2008.1340

Taylor M.C. (2005) Interviewing. In I. Holloway (Ed.), Qualitative research in healthcare (pp. 39-55). Maidenhead, England: McGraw-Hill Education.

Taylor R.J., & Chatters, L.M. (1986). Church-based informal support among elderly blacks. *Gerontologist, 26*, 637-642. doi: 10.1093/geront/26.6.637

Terry, A.J. (2015). *Clinical research for the doctor of nursing practice* (2nd Ed.). Burlington, MA: Jones & Bartlett Learning.

The Henry Kaiser Family Foundation (2008). *Health care costs and the 2008 elections*. Retrieved on October 1, 2016 from www.Kff.Org

Thoma, M.E., McClain, A.C., Louis, J.F., King. R.B., Trumble, A.C., Sundaram, R., & Buck Louis, G.M. (2013). Prevalence of infertility in the United States as estimated by the current duration approach and a traditional constructed approach. *Fertility and Sterility, 99*(5), 1324-1331. doi:10.1016/J.Fertnstert.2012.11.037

Thonneau, P., & Spira, A. (1991) Prevalence of infertility: International data and problems of measurement. *European Journal of Obstetrics, Gynecology and Reproductive Biology, 38*(1), 43-52. doi: 10.1016/0028-2243(91)90206-Z

Thorne, S. (2000). Data analysis in qualitative research. *Evidence-Based Nursing, 3*(3), 68-70.doi:10.1136/ebn.3.3.68

Tight, M. (2016). Phenomenography: The development and application of an innovative research design in higher education. *International Journal of Social Research Methodology, 19*(3), 319-338. doi:10.1080/13645579.2015.1010284

Todres, L., & Holloway, L. (2004). Descriptive phenomenology: Lifeworld as evidence. In F. Rapport (Ed.), *New qualitative methodologies in health and social care research* (pp. 79-98). London: Routledge.

Toscano, S.E., & Montgomery, R.M. (2009). The lived experience of women pregnant (including preconception) post in vitro fertilization through the lens of virtual communities. *Health Care for Women International, 30*, 1014-1036. doi: 10.1080/07399330903159700

Tuohy, D., Cooney, A., Dowling, M., Murphy, K., & Sixsmith, J. (2013). An overview of interpretive phenomenology as a research methodology. *Nurse Researcher, 20*(6), 17-20. doi: 10.7748/nr2013.07.20.6.17.e315 ·

Triandis, H.C. (1994). *Culture and social behavior*. New York: McGraw-Hill, Inc.

Triandis, H.C. (2001). Individualism-collectivism and personality, *Journal of Personality, 69*(6), 907-924. doi:10.1111/1467-6494.696169

Usha Ranji, U., Salganicoff, A., Stewart, A.M., Cox, M., & Doamekpor, L.(2009) State medicaid coverage of family planning services: summary of state findings. Menlo Park, CA: The Henry J Kaiser Family Foundation.

Valvekar, U., Lakshmi, S., & Kumar, A.N. (2016). Hypothyroidism and hyperprolactinemia showed positive correlation in women with primary and secondary infertility. *International Journal of Reproduction, Contraception, Obstetrics and Gynecology, 5*(7) 2079-2083. doi:10.18203/2320-1770.ijrcog20161866

van Ryn, M. (2002). Research on the provider contribution to race/ethnicity disparities in medical care. *Medical Care 40*(1), I140–I151. doi:10.1097/00005650-200201001-00015

Vergani, P., Ghidini, A., Strobelt, N., Roncaglia, N., Locatelli, A., Lapinski, R.H., & Mangioni, C. (1994). Do uterine leiomyomas influence pregnancy outcome? *American Journal of Perinatology, 11*(5), 356-358. doi:10.1055/s-2007-994554

Vergani, P., Locatelli, A., Ghidini, A., Andreani, M., Sala, F., & Pezzullo, J.C. (2007) Large uterine leiomyomata and risk of cesarean delivery. *Obstetrics and Gynecology, 109*(2 Pt 1),410-414. doi:10.1097/01.AOG.0000250470.78700.f0

Verhaak, C.M., Smeenk, J.M. Van Minnen, A., Kremar, J.A., & Kraaimaat, F.W. (2005). A longitudinal, prospective study on emotional adjustment before, during and after consecutive fertility treatment cycles. *Human Reproduction, 20*, 2253-2260. doi:10.1093./humrep/dei015

Verma, I., Sood, R., Juneja, S., & Kaur, S. (2012). Prevalence of hypothyroidism in infertile women and evaluation of response of treatment for hypothyroidism on infertility. *International Journal of Applied and Basic Medical Research, 2*(1), 17-19. doi:10.4103/2229-516X.96795

Ward, E.C., Clark, Le, O., & Heidrich, S. (2009). African American women's beliefs, coping behaviors, and barriers to seeking mental health services. *Qualitative Health Research, 19*(11), 1589–1601. doi:10.1177/1049732309350686

Ward, E.C., Wiltshire, J.C., Detry, M.A., & Brown, R.L. (2013). African American men and women's attitude toward mental illness, perceptions of stigma, and preferred coping behaviors. *Nursing Research, 62*(3), 185-194. doi:10.1097/NNR.0b013e31827bf533

Wechter, M.E., Stewart, E.A., Myers, E.R., Kho, R.M., & Wu, J.M. (2011). Leiomyoma-related hospitalization and surgery: Prevalence and predicted growth based on population trends. *American Journal of Obstetrics and Gynecology, 205*(5), 492.e1–492.e5. doi:10.1016/j.ajog.2011.07.008

Welsh, E. (2002). Dealing with data: Using NVivo in the qualitative data analysis process. *Forum Qualitative Sozialforschung/ Forum: Qualitative Social Research, 3*(2), Art. 26. http://nbn-resolving.de/urn:nbn:de:0114-fqs0202260

World Health Organization. (2006). *Reproductive health indicators for global monitoring: Guidelines for their generation, interpretation and analysis for global monitoring*. Geneva: World Health Organization.

World Health Organization (2010). *Laboratory manual for the examination and processing of human sperm* (5th ed). Geneva: World Health Organization.

World Health Organization (2016). Sexual and reproductive health. Geneva: World Health Organization. Retrieved from http://www.who.int/reproductivehealth/topics/infertility/definitions/en/.

World Health Organization (2013). The importance of a renewed commitment to STI prevention and control in achieving global sexual and reproductive health. Geneva: World Health Organization. Retrieved from http://apps.who.int/iris/bitstream/10665/82207/ 1/WHO_RHR_13.02_eng.pdf

Williams, D.R., & Collins, C. (1997). U.S. socioeconomic and racial differentials in health: Patterns and explanations. *Annual Reviews of Sociology, 21*,349-386.

Williams, D.R., & Mohammed, S.A. (2009). Discrimination and racial disparities in health: Evidence and needed research. *Journal of Behavioral Medicine, 32*, 20-47. doi:10.1007/s10865-008-9185-0

Williams, M.E. (1997). Toward greater understanding of the psychological effects of infertility on women. *Psychotherapy in Private Practice, 16*(3), 7-26. doi:10.1300/J294v16n03_02

Winkelman, W.D., Katz, P. P., Smith, J.F., & Rowen, T.S. (2016). The sexual impact of infertility among women seeking fertility care. *Sexual Medicine, 4*(3), E190-

E197. doi:10.1016/j.esxm.2016.04.001

Wise, L.A., Palmer, J.R., Harlow, B.L., Spiegelman, D., Stewart, E.A., Adams-Campbell, L.L., & Rosenberg, L. (2004). Reproductive factors, hormonal contraception and risk of uterine leiomyomata in African American women: A prospective study. *American Journal of Epidemiology, 159*(2), 113-123. doi:10.1093/aje/kwh016

Wise, L.A., Palmer, J.R., Harlow, B.L., Spiegelman, D., Stewart, E.A., Adams-Campbell, L.L., & Rosenberg, L. (2009). A prospective study of dairy intake and risk of uterine leiomyomata. *American Journal of Epidemiology, 171*(2), 221-232. doi:10.1093/aje/kwp355

Wolf, M. E., Daling, J.R., & Voight, L.F. (1990). Prior cesarean delivery in women with secondary tubal infertility. *American Journal of Public Health, 80*(11), 1382-1383. doi: 10.2105/AJPH.80.11.1382

Wu, A.K., Odisho, A.Y., Washington, S.L.,III, Katz, P.P., & Smith, J.F. (2014). Out-of-pocket fertility patient expense: Data from a multicenter prospective infertility cohort. *The Journal of Urology, 191*(2), 427-432. doi:10.1016/j.juro.2013.08.083

Wu, J.M., Wechter, M.E., Geller, E.J., Nguyen, T.V., & Visco, A.G. (2007). Hysterectomy rates in the United States, 2003. *Obstetrics and Gynecology, 110*(5),1091–1095. doi:10.1097/01.AOG.0000285997.38553.4b

Yu, D. Wong, Y.M., Cheong, Y., Xia, E., & Li, T.C. (2008). Asherman syndrome--One century later. *Fertility and Sterility, 89*(4), 759-779. doi:10.1016/j.fertnstert.2008.02.096

Zegers-Hochschild, F., Adamson, G.D., de Mouzon, F., Ishihara, O., Mansour, R., Nygren, K., Sullivan, E., & Vanderpoel, S. (2009). International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) Revised Glossary of ART terminology, 2009. *Fertility and Sterility, 92*(5), 1520-1525. doi:10.1016/j.fertnstert.2009.09.009

Zegers-Hochschild, F., Adamson, G.D., Dyer, S., Racowsky, C., de Mouzon, J., Sokol, R., Rienzi,L., Sunde, A., Schmidt, L., Cooke, I.D., Simpson, J.L., & van der Poel, S. (2017). The international Glossary on infertility and fertility care, 2017. American Society for Reproductive Medicine. *10*(3), 393-406. doi: 10.1016/j.fertnstert.2017.06.005

Zhang, H., Qi, F., Wang, J., Chen, M. Li, Z., & Zu, X. (2011). Midline prostatic cysts presenting with chronic prostatitis or secondary infertility and minimally invasive treatment: Endoscopic or laparoscopic approach. *Surgical Science, 2*, 285-289. doi:10.4236/Ss.2011.25061

Appendix A: Recruitment Letter

Dear Sir/Madam:

My name is Claudelle Clarke. I am a doctoral student at Walden University completing a degree in Health Sciences. I am requesting your help in posting flyers in your facilities to recruit participants for my doctoral studies on Secondary infertility in African American women. I do not intend to approach participants directly or recruit on site.

Secondary infertility impacts a significant number of women and prevents them from having additional children. The research on African American women experiences with secondary infertility is limited. As a result, the purpose of this study is to shed a light on the experiences of African American women grappling with secondary infertility, to inform clinical practice and add to the research topic.

I am looking to recruit African American women who:

- Are between ages 18-75.
- Have previously given birth regardless of the outcome e.g. still birth, live birth.
- Are currently diagnosed or presenting with secondary infertility.

I am not looking for women who:

- Do not have a uterus
- Choose not to have a second child
- Are actively taking birth control

Everyone who responds to the request to participate will not be included in the study. Only participants who meet the specified inclusion criteria will be allowed to continue with the study. Those who do not meet the inclusion criteria will be notified via phone that they did not meet the inclusion criteria.

The study involves completing a questionnaire about general background and a participant interview. The interview is expected to be one to two hours long. The identity of the participants will not be revealed, and confidentiality is maintained throughout the course of the study. Participation in the study is voluntary and participants will be incentivized with a ten dollar ($10) Chick-Fil-A gift card after completing the study. Enclosed is a recruitment flyer for you to share or post in order to solicit participants.

If you would like to discuss this matter further, or have any questions or concerns about this study, please feel free to contact Claudelle Clarke at [redacted] or at [redacted].

Thank you for your assistance.

Yours Respectfully,

Claudelle Clarke

Appendix B: Recruitment Flyer

My name is Claudelle Clarke. I am currently working on my Doctoral Study in Public Health focusing on African American women struggling with secondary infertility. Secondary infertility is defined as the inability to conceive or carry a pregnancy to term following the birth of one or more children.

I am looking for African American women/Black Women who:

- Are between ages 18-75.
- Have previously given birth regardless of the outcome e.g. still birth, live birth
- Are currently diagnosed or presenting with secondary infertility

I am not looking for women who:

- Do not have a uterus
- Choose not to have a second child
- Are actively taking birth control

Everyone who responds to the request to participate will not be included in the study. Only participants who meet the specified inclusion criteria will be allowed to continue with the study. Those who do not meet the study criteria will be notified via phone that they did not meet the inclusion criteria. Participants not residing locally will use email, phone and/or skype to communicate with the researcher. For local participants, a private meeting room at the [redacted] is set aside to meet with the researcher. All participants will: a) complete a brief questionnaire on demographic information, b) have an initial audio recorded interview to last one to two hours, c) allow for a second interview, if the first interview did not gather all the information for the study, d) receive a following up phone call to complete member checking. Member checking is a process used by researchers to ensure that the information shared in the study by participants is accurately documented. Participant information is kept strictly confidential. An incentive of a ten ($10) dollar Chick-Fil-A gift card is designated for participants who take part in the study.

If you are interested in participating in this study, and would like more information, or know someone who might be interested, please contact: Claudelle Clarke, [redacted] or [redacted]

Appendix C: Screening Questions

1. What is your gender at birth? __Female __Male

2. Have you maintained the same gender throughout your child bearing years?

   __ Yes __No

3. Are you of the African American? __ Yes __ No

4. Are you between the ages of 18- 75? __Yes ___No

5. Are you currently pregnant? __Yes __No

6. Have you been diagnosed with secondary infertility? __Yes __No

7. How long have you had your diagnosis?

   ___Hours __ Days __ Weeks ___Months ___Years

Appendix D: Demographic Questionnaire

Please complete the following Questionnaire. Your answers to the following questions will be used for research purposes only and will be kept strictly confidential.

NAME: ________________________________

PLACE OF BIRTH: ______________________

DATE OF BIRTH: _______________________

OCCUPATION: _________________________

1. Educational Level Completed**:**

   ☐ Elementary School
   ☐ Middle School
   ☐ High School
   ☐ Technical School
   ☐ College
   ☐ Graduate School

2. Age Range:

   ☐ 18-24
   ☐ 25-34
   ☐ 35- 44
   ☐ 45-50
   ☐ 51 and older

3. How do you identify yourself (mark all that apply)?

   ☐ African American
   ☐ Afro-Caribbean
   ☐ African (State which African Country you are from__________)
   ☐ Afro-South American
   ☐ White
   ☐ Hispanic
   ☐ American Indian or Alaskan Native
   ☐ Native Hawaiian or another Pacific Islander Asian
   ☐ Other

4. What is your marital status?

☐ Single (never married)
☐ Married
☐ Divorced
☐ Separated
☐ Widowed

5. Number of children given birth to:___________

b. Outcome: Alive__ Still birth___

6. Ages of the children: ____

7. Have you been diagnosed with secondary infertility? _____________________

8. When were you diagnosed? ____

9. Who diagnosed you?____

10. What is the household income currently? (Check appropriate range)

☐$5,000 or less
☐$5,001 – 10,000
☐$10,001 – 20,000
☐$20,001 – 30,000
☐$30,001 – 40,000
☐$40,001 – 50,000
☐$50,001 – 60,000
☐$60,001 – 70,000
☐$70,001 – 100,000
☐More than $100,000

Appendix E: African American Women Experiences with Secondary Infertility Interview

Thank you for your willingness to participate in research focusing on the experiences of African American women struggling with infertility. I am going to be asking you about your experiences with secondary infertility and its effect on your life.

1. What does having children mean to you?

   Your spouse?
   Your family?

2. What does your vision of a family look like?
   1. **Probe:** How has it changed?
3. What does secondary infertility mean to you?
4. Tell me about your experiences with secondary infertility?
   1. **Probe**: When were you first diagnosed? How did you feel about having secondary infertility? How did it affect you? How did it affect your Spouse? How did it affect your children? How did affect your family members? How did it affect your friends?
5. What kinds of psychosocial stress did you experience?
   1. **Probe**: psychosocial stressors such as depression, anxiety etc.?
   2. How did you manage the psychosocial stressors?
6. How do you manage the challenge of secondary infertility?
7. What kinds of support where to you given by your spouse, family and friends?

8. What information have you shared with your children about secondary infertility?
9. How do you address the questions from your child about having more siblings?
10. How as your diagnosis of secondary infertility affect your interaction with your child? In what ways?
11. Do you know what services are involved in secondary infertility treatment?
    i. **Probe:** Do you know of what services providers are in the community to treat secondary infertility?
    ii. **Prompt:** If you sought fertility treatment, what role/services did they provide?
12. What was your experience with these services?
13. What were their thoughts about these services?
    i. **Probe:** How were you treated by the staff? Were these services sensitive to your needs? If so, in what ways? If not, in what ways?
    ii. **Prompt:** How did you feel when using these services?
14. How easy was it to access services addressing the secondary infertility?
    i. **Probe:** Distance to services? Access to treatment options?
15. What sort of supports do you get from the service providers?
    i. **Probe:** Ask them to relate physical and psychosocial support? Why they would go where they have stated? What sort of concerns were they?
16. What can the infertility treatment services do that would help them to meet the needs of other African American women?

    i. **Probe:** Take them through the needs that they have identified from the above list and ask them to give suggestions that may help to meet these needs?

17. Do you think that there is a need for infertility services to change to meet the needs African American women?
    i. Yes?
    ii. No?
    iii. **Probe:** If yes, what are the changes you feel needs to occur?
    iv. **Prompt:** If yes, what would be the main features of the 'new' service?
18. Is there anything else you like others to know about your experience with secondary infertility?