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Health Care Provider's Perspectives of a Woman's Quality of Life Facing Endometriosis  
and Infertility

by

Bridget J. Ford

A thesis submitted to the faculty of  
Gardner-Webb University Hunt School of Nursing  
in partial fulfillment of the requirements for the  
Master of Science in Nursing Degree

Boiling Springs, North Carolina

2020

Submitted by:

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## Abstract

This study assessed the quality of life of women with endometriosis and infertility issues through the perception of health care providers. The purpose was to increase awareness of the psychosocial aspect of endometriosis to encourage health care providers to incorporate the assessment of the mental health of women diagnosed with endometriosis into care, as well as their partners. The findings of the study showed the importance of providing holistic care to women with endometriosis related infertility and the vast impact endometriosis has on mental health, relationships, and in a woman's daily life. Implications for nurses as a result of the findings suggest that the evaluations of mental health should be included into the care of woman diagnosed with endometriosis.

*Keywords:* endometriosis, woman, infertility

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## **CHAPTER I**

### **Introduction**

Endometriosis is “the presence of endometrial-like tissue (glands and stroma) outside the uterus” (Khine et al., 2016, p. 217). As a result, many women with endometriosis experience pain, sexual concerns, and fertility challenges. Endometriosis is an illness that is mostly overlooked due to incomprehension from peers, employers, partners, and family. As a result, women with endometriosis are left feeling isolated, misunderstood, and broken (Aerts et al., 2018). This illness affects the body in more than one way; from the emotional dismay to the unbearable pain, women with endometriosis are forced to conceal their personal feelings and thoughts due to the lack of knowledge surrounding the illness. The effect of the quality of life of women with endometriosis and their relationships in conjunction with infertility is seldom addressed (Aerts et al., 2018).

Endometriosis can have a mental and physical impact on a woman's life. The pain that is often associated with endometriosis has an effect on a client's employment, education, daily activities, and relationships. Most individuals who have been diagnosed with endometriosis also struggle to conceive. Infertility plays a huge role in the effects of endometriosis on relationships and a women's mental stability. For a woman not to be able to bare children her self-image may be drastically impacted, which may negatively affect intimate relationships (Rush & Misajon, 2018). Often the emotional portion of the diagnosis is overlooked. Most physicians focus on the physical effects of endometriosis and do not wish to go beyond that. Some physicians attribute their abandonment of the emotional aspects of infertility with endometriosis to the idea that it is not within their scope of practice, while others solely state that they were simply not trained to explore

the emotional sides of an illness (Young et al., 2017). Family members, peers, and even partners are left with the misunderstanding of what endometriosis truly entails, leaving them unsure of how to comfort a loved one since the emotional aspect of endometriosis related to infertility is often neglected (Rush & Misajon, 2018). Therefore, the purpose of this study was to assess the health care providers perspective on the quality of life of women with infertility related to endometriosis.

### **Significance**

The treatment of endometriosis as a holistic approach is rare. Most individuals who do not suffer from this illness fail to see the hardships that accompany this disease. The large number of areas that endometriosis affects in a person's life and relationships are not considered, and when the emotions behind endometriosis are unlocked, they are poorly addressed (Young et al., 2017). Researching the quality of life of women with infertility related to endometriosis will expand the knowledge of physicians, friends, family, and partners on the emotional concerns that accompany this diagnosis and promote the provision of holistic care.

This study will aid in the enlightenment of health care professionals, employers, and peers. It will allow members of the health care team and others to get a better understanding of endometriosis, which entail will assist in the formation of a better support system. Endometriosis is an illness that is rarely discussed; as a result, there is a lot of misinformation that is communicated or understood. Though it may be difficult for one to have a concrete understanding of endometriosis, it should be clear how it affects that individual (Aerts et al., 2018). Endometriosis can have such a direct effect on an individual's daily activities, making it imperative that it is accurately understood. This

study will give the health care professionals, colleagues, employers, educators, family, friends, and partners insight into a woman's life who suffers from endometriosis and its emotional burden as it relates to infertility from the perspective of health care providers.

### **Purpose**

The purpose of this study was to examine the quality of life of women with infertility issues due to endometriosis from the perspective of the health care provider. It may take half a decade before endometriosis is diagnosed. Most individuals fail to even realize an issue until they discover fertility problems (Rush & Misajon, 2018). As a woman, being told that they may not be able to get pregnant may lead to a widespread of emotions that causes them to feel minute. Having the ability to reproduce can be seen as an unwritten decree that women must bear children, which in turn leaves a woman feeling hopeless (Rush & Misajon, 2018). Ensuring that these feelings are addressed with endearment and purpose was the primary goal of this study.

“Endometriosis is defined as the presence of endometrial glands and stroma like lesions outside of the uterus” (Parasar et al., 2017, p. 2). The endometrial tissue found outside of the uterus can form adhesions which may disrupt the normal function of the uterine tissue making it difficult for an oocyte to attach and grow into a fetus. These adhesions may also cause excruciating pain that may interfere with daily activities and relationships. Most clients with endometriosis complain of unbearable pain that affects their sexual experience, urinary and bowel elimination, and menstrual cycle. These symptoms play a role in the quality of life of a woman who carries the diagnosis of endometriosis (Parasar et al., 2017).

Some may argue that being alive does not always coincide with living your life.

Being able to live your life involves being secure mentally, financially, and even physically. These are all factors that are heavily affected by endometriosis. Mentally, a client can be emotionally drained by endometriosis for numerous reasons, such as treatment cost, being misunderstood, physical discomfort, and the fear of infertility. As with other illnesses, the disease should be addressed holistically. Though a person's perception of their quality of life may not be physically visible, it is just as important (Lukas et al., 2018).

Endometriosis threatens the peace of individuals and their respective futures. When a woman is informed of the abnormal location of the endometrial tissue that resides outside of the uterus, she is confronted with the question of carrying children. Procreation is a natural function of women's reproductive system. When that system becomes dysfunctional it can cause a woman to panic. That panic and uncertainty can easily filter into their careers, relationships, and disrupt their mindset. Most women with endometriosis suffer from pelvic pain, which also adds to the resistance to participate in sexual activity. In serious relationships, carrying the fear of not being able to get pregnant has a negative impact on the relationship (Aerts et al., 2018). All factors play a role in women diagnosed with endometriosis and should each be incorporated in patient care.

### **Research Questions**

This study addressed the following research questions:

1. What role have you witnessed that endometriosis plays in women's work life, social life, intimate relationships, potential or diagnosed infertility, and mental health?
  - a) Which areas are identified from women as most important?

2. To what extent do you think infertility affects women with endometriosis?
3. Who is responsible for the psychosocial care of women with endometriosis?
4. Should the psychosocial aspect of infertility be included in patient care of women diagnosed with endometriosis?
  - a) If so, how?

(Young et al., 2015; Facchin et al., 2019)

### **Theoretical Framework**

Health care providers should have the knowledge to provide concrete care and the compassion to implement it. The concept of human caring goes hand in hand with the provision of safe and holistic patient care. Most health care providers are familiar with interdisciplinary care as it has become a widely accepted and highly respected holistic approach to patient centered care. Understanding that there are different factors that can influence a patient's health, while there are various instances in which one event or diagnosis can affect more than one aspect of a patients' health allows health care providers to take more of an interest in the psychological well-being of a patient. The Theory of Human Caring by Jean Watson addresses the imperative dynamics of incorporating the element of caring for an individual, a team, and yourself as incredibly mandatory to provide quality care (Wei & Watson, 2019).

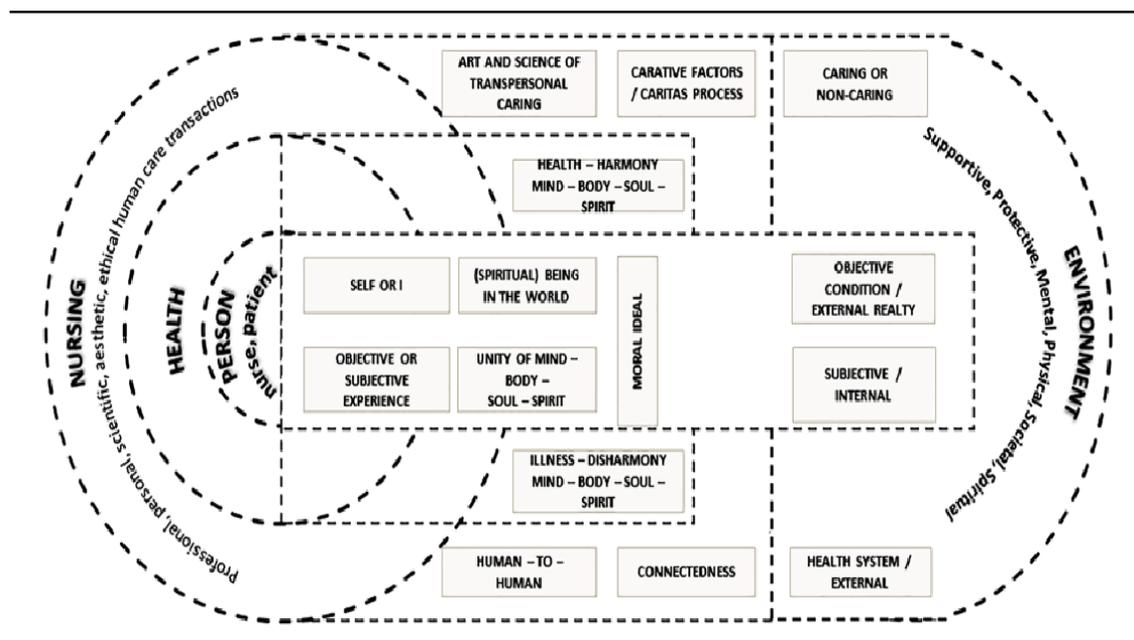
The Theory of Human Caring by Jean Watson highlights the importance of exhibiting care towards an individual and the beauty of demonstrating self-love, care for others, and care for a team to promote quality patient care. "Human caring . . . is transpersonal (between human beings and across disciplines), intentional (purposeful), and transcendent (uplifting), which affects the unitary field of the whole system of a

human being and the dynamics of an interprofessional team” (Wei & Watson, 2019, p.22). Using the interdisciplinary approach to address patient care allows the patient to be examined in all aspects of health. It also allows the patient to receive quality care from each disciplinary team using their knowledge and expertise to better assist the client to reach their optimal level of health in all aspects of health. Patients are more than just their physical health, there is also an emotional factor of health which is equally important (Wei & Watson, 2019). As a health care provider, all aspects of health should be addressed.

The Human Caring Theory will be utilized as the theoretical framework to examine the quality of life of women with infertility related endometriosis from the perspective of health care providers. The Human Caring Theory is a well-respected theory that has been incorporated into practice across disciplines. It exemplifies the needed ability to address all aspects of a client’s health. Physicians often solely focus on the physical ailments that occur because of endometriosis. They neglect to address the emotional concerns a woman and her partner may have with conception or they briefly acknowledge it (Ameratunga et al., 2017). Assessing the emotional impact women face who suffer from infertility from endometriosis is rarely discussed, which does not ensure all the patient's needs are adequately met. Figure 1 illustrates The Human Caring Theory model as developed by Jean Watson.

**Figure 1**

*The Human Caring Theory Model. This figure illustrates the Watson Human Caring Theory in a model form (Psych Mental Health NP Resources and Support, 2020).*



### Definition of Terms

- Infertility.** “Infertility is defined as not being able to get pregnant (conceive) after one year (or longer) of unprotected sex” (Centers for Disease Control [CDC], 2020b, para. 1).
- Quality of Life.** “Quality of life (QOL) is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life” (CDC, 2020a, para. 1)
- Endometriosis.** “It is defined as the presence of endometrial-like tissue (glands and stroma) outside the uterus” (Khine et al., 2016, p. 217).

The purpose of this study was to examine the quality of life of women with infertility issues due to endometriosis from the perspective of the health care provider. It may take half a decade before endometriosis is diagnosed. Most individuals fail to even realize an issue until they discover fertility problems (Rush & Misajon, 2018). As a woman, being told that they may not be able to get pregnant may lead to a widespread of emotions that causes them to feel minute. Having the ability to reproduce can be seen as an unwritten decree that women must bear children, which in turn leaves a woman feeling hopeless (Rush & Misajon, 2018). Ensuring that these feelings are addressed with endearment and purpose was the primary goal of this study.

## CHAPTER II

### Review of Literature

The ability to review the literature provided a better understanding of the topic, increased understanding of the extent to which the topic was assessed, and shined light on the importance of the given topic. Various words and phrases were entered as a search strategy to gain a better understanding of the quality of life of women with endometriosis as it relates to infertility. The following key words and phrases were used:

“endometriosis,” “quality of life of endometriosis,” “assisted reproductive technology and endometriosis,” “endometriosis and infertility,” “male partners and endometriosis,” “contraception and endometriosis,” “endometriosis and fertility,” “endometriosis and pregnancy rates,” “psychosocial and endometriosis,” and “endometriosis and miscarriage.” The Gardner-Webb University library database and Google scholar were used to locate informative journal research articles.

#### Quality of Life of Endometriosis

Endometriosis plays a direct role in the quality of life of women with endometriosis. Young et al. (2015), a literature review on qualitative research studies to highlight the effect of endometriosis on the quality of life of women due to the lack of research on the psychosocial aspect of endometriosis. Endometriosis is an illness that can cause hypermenorrhea, dysmenorrhea, dyspareunia, and infertility. As a result, some women would refrain from engaging in intercourse while others would attempt to try different sexual positions to alleviate the pain. Partners were also affected by this as they reported feelings of discontentment. Women also experienced discontentment and shame for not being interested in please their partner sexually. Symptoms of endometriosis also

affect women work and social lives. Some women cancel plans out of fear of experiencing pain or bowel issues around friends and family. The lack of understanding of endometriosis also causes some women to hide their illness from employers and physicians. Many women reported feeling that the physicians were not knowledgeable about the illness themselves. Their lack of therapeutic communication also interfered with their relationship with their health care provider. The inferred emotional distress that often accompanies the diagnosis of endometriosis is self only addressed or ignored, leaving women feeling hopeless and empty with no clear direction or encouragement (Young et al., 2015).

Abd El-Kader et al. (2019) conducted a descriptive research study to examine the relationship between endometriosis and quality of life in relation to adhesion development. One-hundred and nine women were selected to participate in the study who were scheduled to receive laparoscopy surgery to diagnosis the presence of adhesions and who were experiencing infertility issues. Endometriosis can occur due to the formation of adhesions, which are a type of tissue that interferes with the function of the ovaries and uterus by combining varies tissue types that should be separated. As a result, these adhesions can affect fertility, the gastrointestinal system by affecting bowel elimination, and cause excruciating pelvic pain throughout the course of their life. Unfortunately, though adhesions can be surgically removed, they are prone to return in women diagnosed with endometriosis. The results of the study revealed that nearly have of the participants with endometriosis revealed to have adhesions, as well. Women suffering from chronic pain and infertility, due to adhesion, expressed a decreased quality of life (Abd El-Kader et al., 2019).

Rush and Misajon (2018) organized a research study highlighting the quality of life of women with endometriosis and their partners. In the study women and their partners were encouraged to verbalize their emotions and concerns regarding the uncommon diagnosis of endometriosis. To participate in the study subjects must be 18 or older, with a medical diagnosis of endometriosis, and fluent in the English language. Various techniques were utilized for participants recruitment such as convenience sampling, social groups, and social media websites. Data was collected from 500 participants who completed the online surveys. Data was collected via the Endometriosis Profile Questionnaire in combination with open-ended questions that highlighted the quality of life of women with endometriosis from the patient's perspective. In relation to infertility, most women's fear or inability to conceive caused other unsettling emotions to arise concerning their relationship (Rush & Misajon, 2018). "I felt as though I wasn't woman enough for my ex-partner. I couldn't give him what I wanted to be able to. It caused me to become quite a paranoid partner, constantly expecting him to cheat or leave me for someone else" (Rush & Misajon, 2018, p. 314).

Endometriosis plays an excruciating role in each aspect of a woman's' life. Aerts et al. (2018) explored the influence endometriosis had on women's daily life, relationships, and their mindset. Aerts et al. (2018) conducted a literature review on research articles, cross sectional studies, and qualitative research studies to gain knowledge of the psychosocial struggles of endometriosis. With endometriosis affecting young women it may hinder or greatly delay a student from obtaining a degree. Some working women even insist on keeping their diagnosis from their supervisor due to the ignorance that surrounds the illness (Aerts et al., 2018). Mental health is also impacted

due to the hope of a positive pregnancy test. Women feel as though their value as a woman has been depreciated or threatened by the difficulty of bearing children. The emotional struggles that coincide with infertility have been addressed in several studies; however, the emotional battle of infertility and its association with endometriosis has been neglected (Aerts et al., 2018).

Khine et al. (2016) performed a literature review on multiple articles to examine the relationship between endometriosis and infertility and to acknowledge treatment options available for infertility related to endometriosis. Research articles, meta-analysis, and randomized control studies through 2015 were assessed to receive a dynamic understanding of the mechanism of endometriosis and effective treatment modalities. The studies proposed that although endometriosis can affect various organs of the female reproductive system, the ovaries have been shown to be the most targeted organ in endometriosis. As a result, infertility is thought to be the result of ovary and endometrial dysfunction (Khine et al., 2016). More and more women are personally associated with the diagnosis of endometriosis (Khine et al., 2016). “Prevalence of endometriosis has increased up to 50 % in women with infertility” (Khine et al., 2016, p. 217).

Experiencing infertility, as a woman, can affect self-image and interfere with their perceived role drastically. Facchin et al. (2019) conducted a research study to identify the relationship between women with endometriosis regarding infertility and self-image. One hundred ninety women diagnosed with endometriosis were utilized during the study. Women with additional diagnosis, including mental and physical, were excluded from the study. Out of 190 participants 127 participants did not carry the title of a mother. Participant’s perceptions of infertility and self-identity were examined by using the

hospitals' Anxiety and Depression scale, Rosenberg self-esteem scale, and a questionnaire developed using the Likert-type scale to assess women's perception of maternity and self-image. The difficulty that persists after one year of attempting conception has increased, leaving women feeling hopeless and irrelevant to society (Facchin et al., 2019).

### **Psychosocial Impact of Endometriosis**

Most physicians tend to solely focus on the physical characteristics of endometriosis and fail to address all the areas that endometriosis can impact such as career and relationships. Young et al. (2017) conducted a qualitative study that highlighted the role of endometriosis in a woman's daily life from the perspective of the health care provider. Twelve clinicians were chosen via purposive sampling and were interviewed concerning their perspective of how endometriosis may have a personal impact on a woman's life and their knowledge or approval of comfort measures during patient encounters. Some doctors view this as care for an interdisciplinary team and not from them, while others do not deem it necessary to discuss at all. According to Young et al. (2017), “. . . the psychosocial consequences of endometriosis are not considered a research priority by the World Congress of Endometriosis delegates nor is psychosocial care explicitly addressed in the current leading clinical guidelines” (p. 88).

Endometriosis makes more than a physical impact on the patient, but it also affects intimate relationships. This diagnosis can have a negative impact on the person's life, relationships, and well-being (Young et al., 2017).

The effect of endometriosis on relationships are ignored and rarely addressed. Ameratunga et al. (2017) conducted research addressing the quality of life of women with

endometriosis and their relationships. Women were selected via hospital database if they were older than 18 with a medical diagnosis of endometriosis as their sole morbidity. They utilized questionnaires to collect data from the perspective of women and their partners to get an idea of women's' and partners perceptions of daily life in various aspects (Ameratunga et al., 2017). "The majority of these respondents revealed frustration and worry about the diagnosis and interestingly many commented about feeling helpless and not knowing how they could help their partners. Many also conveyed the frustration felt at the delay in diagnosis and disengagement with their medical practitioners" (Ameratunga et al., 2017, p. 1051). Incorporating emotional relationship support as a part of treatment completion can improve clients' relationships and treatment outcome (Ameratunga et al., 2017). Intimacy is seen as a vital factor in a healthy relationship. Though it may not be the central puzzle piece to all relationships it is viewed as an important factor to maintain a healthy relationship. In relationships that are affected by endometriosis, women may refrain from engaging in intercourse due to pain or the idea of the possibility of not being able to conceive. This may present as a difficult challenge to overcome in a relationship, which results in a poor companionship (Ameratunga et al., 2017).

Lukas et al. (2018) conducted a multi-center retrospective cohort study that highlighted women's content with medical and mental support. Women were selected if they had a medical diagnosis of endometriosis with a confirmed stage. Questionnaires were used and completed by 500 participants. Most women were chosen from hospitals and some support groups. Many women felt as though their relationship involvement with their diagnosis was rarely discussed. The emotional aspect of infertility seemed to be

less important to health care providers than medical treatment. Making women's relationships who suffer from endometriosis more of a priority in treatment may yield positive results. It is an issue that should be more actively addressed (Lukas et al., 2018).

Matasariu et al. (2017) conducted a cross-sectional study to examine the relationship between quality of life and endometriosis as it relates to mental health. Two-hundred and five women between the ages of 18 and 42, diagnosed with endometriosis, participated in the study. The Fertility Problem Inventory, which assessed stress caused by infertility, the Endometriosis Health Profile, which assessed the quality of life of women with endometriosis, and the Beck Depression Inventory, which examined signs and symptoms of depression, were the questionnaires that were utilized in the study. Women diagnosed with endometriosis may experience symptoms that could interfere with their daily life, such as chronic pelvic pain. They also tend to suffer from infertility issues that affects their relationships, both sexually and emotionally, and their mental health. Struggling with the fear of not being able to have children causes an emotional strain on patients and their partners. The results of the study showed that infertility related to endometriosis has a major impact on his contribution to the development of anxiety and depression. Women also reported their dismay regarding missing work due to pelvic pain. Some women explained a lack of interest in engaging in sexual activity due to the emotional strain of possibility not being able to conceive (Matasariu et al., 2017).

### **Endometriosis and Infertility**

Tanbo and Fedorcsak (2017) conducted a literature review utilizing the PubMed, Medline, and Embase databases. They examined studies conducted in 2016 concerning the association between endometriosis and infertility and available treatment options. The

studies found that the relationship between endometriosis and infertility is classified by the severity of the disease. Women with mild endometriosis have a higher chance of natural conception versus women in the advanced stage of endometriosis (Tanbo & Fedorcsak, 2017).

The exact association of infertility and endometriosis is unknown. Research has shown that endometriosis has a significant impact on the natural conception of women with endometriosis without the support of assisted reproductive technology (Tomassetti & D'Hooghe, 2018). Tomassetti and D'Hooghe (2018) analyzed the correlation between endometriosis and infertility and gathered treatment modalities. The type of treatment for endometriosis should be determined based on the patient's desire to conceive as some medications utilized to treat pelvic pain associated with endometriosis may inhibit a woman from conceiving a child. For example, combined oral contraceptives are an option for pain management, but it does decrease the chance of conception. Laparoscopic surgery is also an option for pain management, and it can increase the chance of pregnancy in a woman with mild endometriosis (Tomassetti & D'Hooghe, 2018). However, it may not have much impact on women in the moderate or severe stage of endometriosis as the attachment of the embryo to the endometrial tissue may not be possible (Tomassetti & D'Hooghe, 2018).

De Wilde et al. (2016) examined the physiology behind adhesions as the causal factor in infertility related to endometriosis. This study examined the adhesions to be one of the causes behind infertility as it disrupts the normal function of the reproductive system. They determined that a woman is usually classified as infertile prior to the diagnosis of endometriosis. Due to the adhesions, surgery in some cases are encouraged;

however, the understanding that they are likely to return is discussed. (De Wilde et al., 2016).

Porpora et al. (2020) conducted an observational study to evaluate the effects endometriosis has on pregnancy, birth, and neonatal complications. Four hundred and twenty-five Caucasian women were selected to participate in the study. Of this sample, 145 women were diagnosed with endometriosis and 280 women were not a victim of the disease. To be eligible to participate in the study the women must also be classified as primiparous and older than 17. As a result of the study, it was observed that laparoscopic surgery enhances the ability for women to become pregnant. It was shown that most women with endometriosis become pregnant not long after surgery (Porpora et al., 2020).

Zorbas et al. (2015) performed a systematic review that only included articles that followed participants who received oral contraceptives following surgery. Though in most cases completion of laparoscopic surgery for the treatment of endometriosis is considered the more favorable treatment option for endometriosis in relation to pelvic pain and conception, oral contraceptives can also be used to manage symptoms of endometriosis. Though hormonal medications may assist with some symptoms of endometriosis, selecting this course of treatment may not be the best for every patient with this illness as surgery is able to address the manifestations of both infertility and pelvic pain for most patients with mild endometriosis (Zorbas et al., 2015).

Khine et al. (2016) evaluated multiple articles to identify the correlation between infertility and endometriosis and treatment methods that could assist with fertility. Many studies have been conducted to explore the possible benefits of endometriosis treatment prior to the initiation of assisted reproductive technology (Khine et al., 2016). While

some hormonal medications or surgery prior to fertility treatment may increase the chance of pregnancy, it may also inversely affect pregnancy outcomes. As a result, it is imperative to assess the patient's age, stage of endometriosis, and pain severity to formally suggest the best course of action. In vitro fertilization, which is a type of assisted reproductive technology, can enhance the chance of pregnancy in women with endometriosis who struggle to conceive (Khine et al., 2016).

Ruiz-Flores and Garcia-Velasco (2016) analyzed multiple articles to gain a better understanding of the management options for clients who suffer from infertility due to endometriomas, which have a known association with endometriosis. In this case, most clients are encouraged to pursue assisted reproductive technology initially, as it is less invasive and yields the same pregnancy results as surgery; however, each client's situation should be individually examined. Some patients may have an increased chance of pregnancy if they begin assisted reproductive technology modalities prior to surgery, while others may benefit more by investing in surgery as the initial treatment (Ruiz-Flores & Garcia-Velasco, 2016).

The most common type of assisted reproductive technology is IVF or in vitro fertilization. In women who present with endometriosis, it has been shown to be more effective to attempt the fertilization of one embryo versus multiple to increase the probability of a healthy pregnancy and baby (Feichtinger et al., 2019). Feichtinger et al. (2019) conducted a cross-sectional case-control study of the effectiveness of IVF with single embryo transfer with women diagnosed with endometriosis compared to women without the disease. 2,757 women with endometriosis were compared to 2,585 women without the illness to measure IVF effectiveness. Ovarian sensitivity index was used to

evaluate effectiveness and the number of oocytes present were assessed. The study showed that IVF is equally as effective in women with endometriosis as women without it.

In a study conducted by Yang et al. (2019), the complication of miscarriage following the use of IVF in women with endometriosis and without it was assessed in a retrospective cohort study. One thousand six women with endometriosis who have undergone laparoscopic surgery prior to IVF therapy were selected. Women diagnosed with endometriosis must also have never participated in IVF prior to the study and are only receiving single embryo transfers. 2,012 women without endometriosis were used as the control group. Research showed that the risk of miscarriage is not elevated in women with endometriosis succeeding assisted reproductive technology (Yang et al., 2019).

Mathiasen et al. (2018) conducted a cohort study to examine the effects of symptoms of endometriosis with assisted reproductive technology. Fifty-two women with endometriosis were examined and compared to women without endometriosis and women with endometriosis, who were not participating in assisted reproductive technology. Questionnaires and pain assessments were utilized to compare each group of clients. The study revealed that women with endometriosis expressed a higher quality of life and decrease in pain sensation in relation to women without endometriosis and those with endometriosis who did not undergo Assisted Reproductive Technology (ART). Pain is not heightened by the utilization of assisted reproductive technology. Therefore, though assisted reproductive technology may not be the best method for every endometriosis patient, it is a safe option for some who desire pregnancy (Mathiasen et al., 2018).

González-Comadran et al. (2017) organized a retrospective cohort study to assess the differences in pregnancy outcomes in women with infertility associated to endometriosis and women with infertility issues unrelated to endometriosis. With the assistance of 22,416 women who participated in this study, it was determined that the effectiveness of assisted reproductive technology depends on various aspects of the client, such as the type of endometriosis, the age of the client, and the presence and number of viable oocytes (González-Comadran et al., 2017). However, the health of the child at birth was not affected by the use of ART in women with infertility related endometriosis.

### **Strengths and Limitations**

Endometriosis affects every aspect of a person's life. The daily effects that endometriosis has on women and their partners are often overlooked or misunderstood. The literature supports the idea that endometriosis has a tremendous impact on women's daily lives and natural conception. Often infertility is an indicator of endometriosis. Although endometriosis and infertility have been shown to be related, the emotional support behind it is non-existent (Young et al., 2017). The limitations of the literature are displayed with the various forms and causes of endometriosis, such as the development of adhesions. Another limitation of the literature is the continuous perplexity of the pathophysiology of endometriosis (Aerts et al., 2018). As a result, the purpose of this study was to examine the quality of life in women with endometriosis as it relates to infertility from the perspective of health care providers.

## **CHAPTER III**

### **Research Design**

A descriptive research design was utilized in this study to determine the quality of life of women who suffer from infertility related endometriosis from the perspective of health care providers. A questionnaire from Survey Planet, containing four open-ended questions were sent to participants via a link on the e-mail. The results collected from the questionnaires may enhance the understanding of the social and emotional impact infertility plays on women with endometriosis. Six health care providers were invited to participate in this study. The qualitative data that was collected may allow physicians, health care workers, clinicians, family members, and employers to gain an unconventional insight into the emotional desires of women diagnosed with infertility related to endometriosis from the perspective of health care providers.

### **Setting and Sample**

The setting took place within The Family Planning Services Department at a public health facility in an urban city within the southeastern United States. The Family Planning Services department has trained health care professionals, such as nurse practitioners and registered nurses, to provide quality patient care. Data was collected electronically. The link for the questionnaires was sent to participants via e-mail by the department supervisor.

A convenience sample of six health care providers were contacted via e-mail to participate in the survey. To participate, participants must currently be employed in The Family Planning Department and have had direct encounters with endometriosis patients. Participants were contacted via e-mail concerning the purpose of the survey, received

informed consent, and received a link for the questionnaire to be completed electronically.

### **Protection of Human Rights**

To ensure the rights of human participants were protected, an application was submitted to the Institutional Review Board (IRB) at Gardner-Webb University. This study was approved by the board prior to the administration of questionnaires. The researcher also received permission from the department supervisor in which the study was conducted. Each participant willingly volunteered to participate in this study to enhance the understanding and educate health care providers on the importance of addressing the psychosocial aspect of women who suffer from infertility related to endometriosis. Each participant was contacted via e-mail, which included information on the purpose of the study and informed participants that they can refrain from participating at any time. Participants were provided with this information in the informed consent as well. Health care providers were also assured that the data collected on the surveys was confidential and their personal identity was not to be included in the study.

### **Instruments**

A self-report questionnaire was utilized for data collection during this study; the questionnaire was created on Survey Planet. The self-report questionnaire allowed health care providers to express their perception of the quality of life of women with endometriosis and fertility issues. Qualitative data was collected from the self-report questionnaire. The questionnaire consisted of four open-ended questions that inquired about women diagnosed with endometriosis and the perceived importance of emotional acknowledgement by health professionals. This instrument measured the emotional and

social effect infertility has on women with endometriosis and their relationships. The four open-ended questions utilized in the survey were based on the research of Young et al. (2015) and Facchin et al. (2019) and were listed as follows:

1. What role have you witnessed that endometriosis plays in women's work like, social life, intimate relationships, potential or diagnosed infertility, and mental health?
  - a. Which areas are identified from women as most important?
2. To what extent do you think infertility affects women with endometriosis?
3. Who is responsible for the psychosocial care of women with endometriosis?
4. Should the psychosocial aspect of infertility be included in patient care of women diagnosed with endometriosis?
  - a. If so, how?

### **Data Collection Procedure**

Prior to IRB approval, more than twenty research articles were analyzed and included in the literature review. Four-open ended research questions were developed to assess the quality of life of women with endometriosis as it relates to infertility, from the health care providers perspective, which was electronically constructed via Survey Planet. Once the IRB and the research facility approved the research study, the perception of health care providers was used to assess the quality of life of women with infertility related endometriosis. A self-report questionnaire was utilized for data collection. The link for the questionnaire from Survey Planet was distributed via e-mail to participants. The link was sent to the nursing supervisor of the family planning department, who forwarded the e-mail to registered nurses and nurse practitioners in the department. The

participants were contacted via e-mail and the purpose of the research study, the consent form, and the link for the questionnaire were provided.

### **Data Analysis**

All completed surveys were electronically submitted via Survey Planet. Responses were evaluated and compared with other participants' replies and later reflected on a spreadsheet for comparison and easy reference. Participants identities were not included in the analysis. All entries included in the spreadsheet were made anonymous. Once the spreadsheet was completed, each participant's response was analyzed for themes by the researcher and faculty advisor.

## **CHAPTER IV**

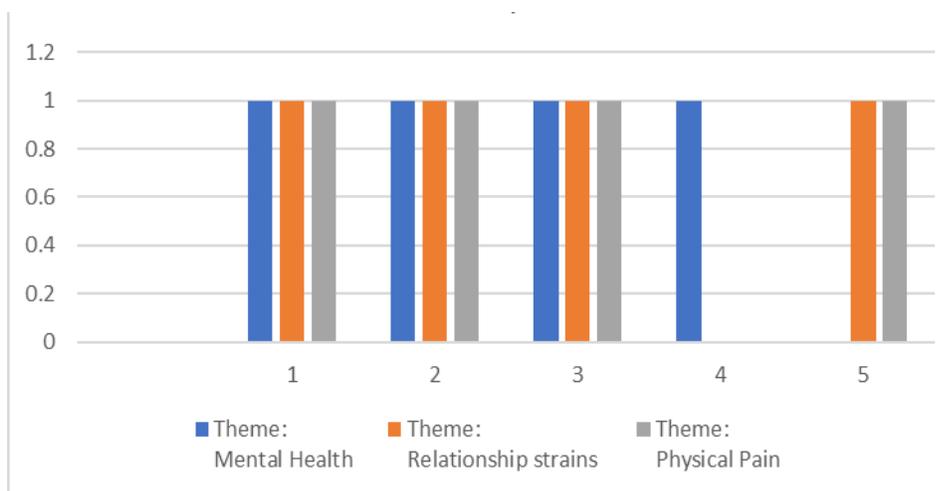
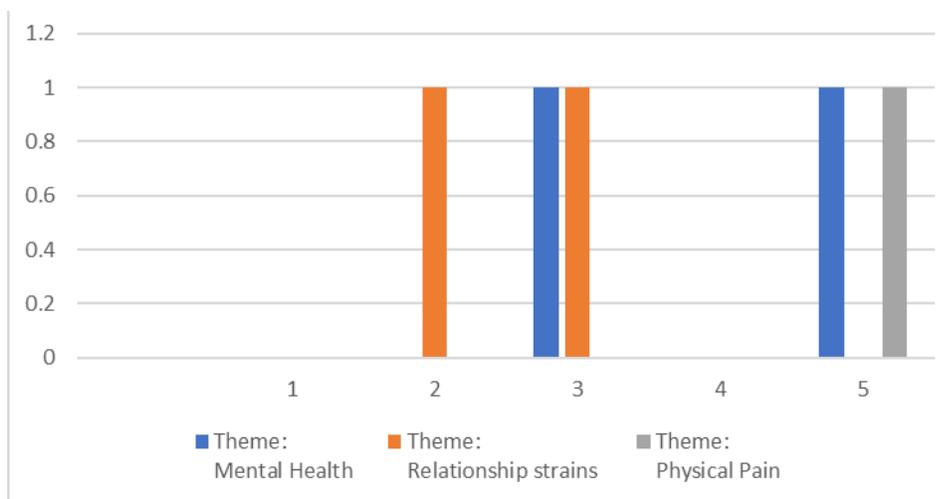
### **Results**

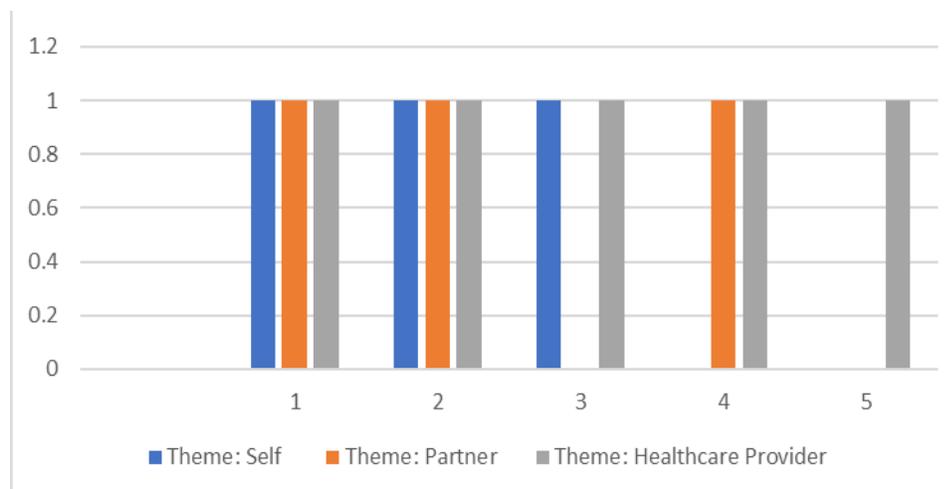
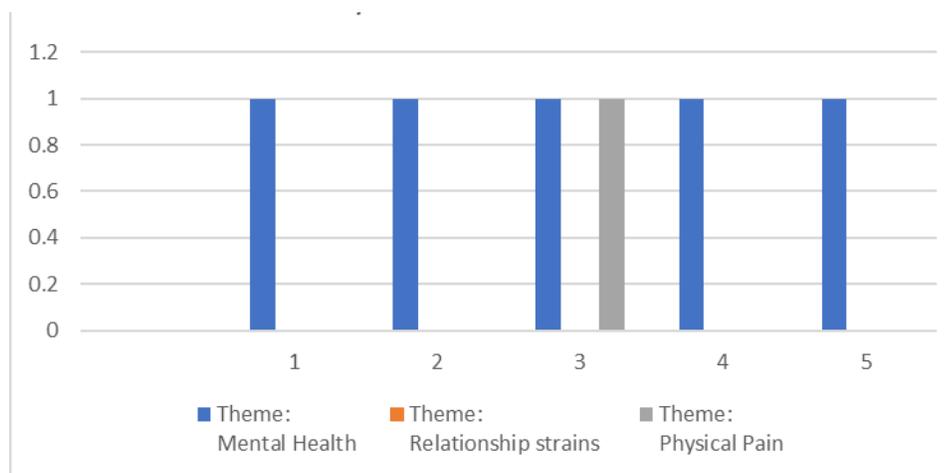
The purpose of this study was to assess the relationship between endometriosis, infertility, and the quality of life of women from the perspective of the health care provider to increase the awareness of the needed acknowledgment of the psychosocial health of women diagnosed with endometriosis. The goal was to encourage health care providers to incorporate the client's psychosocial health in the care plan for women diagnosed with endometriosis. Often the mental health of clients is neglected. It is essential health care providers to ensure the provision of holistic patient care to address the needs of the patient as a whole.

#### **Sample Characteristics**

The link for the survey was distributed via e-mail. Out of the expected completion of six surveys, five were completed (n=5), yielding a response rate of 83%. Nurse practitioners and registered nurses were invited to participate in the study.

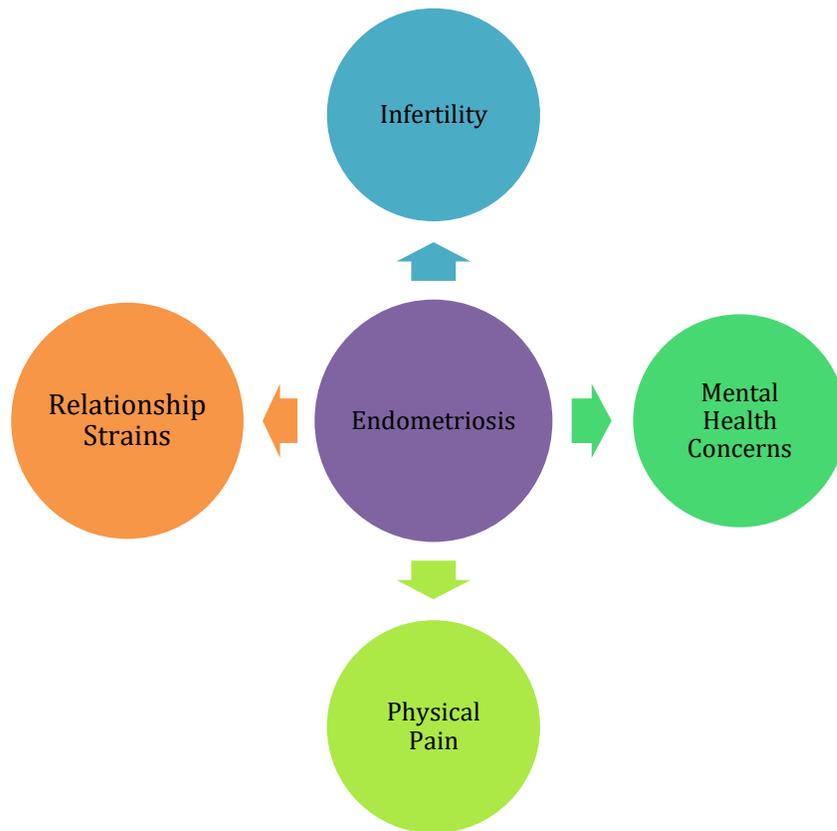
The results for each survey questions are displayed in Figures 2-5 below. Additionally, Figure 6 illustrates the primary themes, which show The Influence of Endometriosis on the Quality of Life of Women.

**Figure 2***Endometriosis Influence on Infertility and Quality of Life***Figure 3***Infertility's Effect on Endometriosis*

**Figure 4***Responsibility of Psychosocial Care in Endometriosis***Figure 5***Is Endometriosis Associated with Psychosocial Health?*

## Figure 6

*The Influence of Endometriosis on the Quality of Life of Women. This figure illustrates themes associated with endometriosis.*



## Major Findings

Figure 2 examines the role endometriosis plays in the quality of life of women in various aspects of an individual life, such as the workplace, social environment, and relationship. It also assesses the effect of infertility in women diagnosed with endometriosis and the psychosocial health it may affect. The common themes that continued to populate in most responses were mental health, relationship strains, and physical pain. Sixty percent of participants stated that all three themes: mental health,

relationship strains, and physical pain were all influenced by endometriosis. Out of all five respondents, 80% stated that mental health was a result of endometriosis, 80% stated that relationship strains are a product of endometriosis, and 80% stated that physical pain was related to the quality of life of women who suffer from endometriosis.

Figure 3 examines the effect infertility has on women with endometriosis. Fifty percent of participants believe infertility related to endometriosis causes relationship strains. Fifty percent of participants also believed infertility issues caused by endometriosis, can also lead to mental health concerns. Infertility is not just seen as a physical abnormality, but it can affect relationships and have a negative impact on the mental health of women with endometriosis and their partners.

Figure 4 illustrates the perceived responsibility of the psychosocial care of endometriosis from the perception of the health care provider. One hundred percent of participants stated the responsibility of addressing the psychosocial aspect of care of women diagnosed with endometriosis belonged to the health care provider. Sixty percent of participants stated the responsibility belonged to the partner and 60% of participants stated the patient themselves are responsible for their mental health. Though the responsibility of ensuring the mental health of a patient diagnosed with endometriosis seems to be divided between self, partners, and the health care providers, all of the participants agreed that it should be addressed by the health care provider.

Figure 5 examined the correlation between psychosocial health and endometriosis. One hundred percent of participants stated that mental health concerns are related to endometriosis. The correlation that endometriosis has on the mental health of individuals diagnosed with endometriosis confirms the need for psychosocial health to be

incorporated in the patients plan of care. Assessing the client's health status as a whole must be routinely included in the patient care of women with endometriosis.

Figure 6 displays the relationship between endometriosis, physical pain, relationship strains, and mental health concerns. Endometriosis plays a role in each, with a heavier influence on mental health concerns. The emotional strain that accompanies the diagnosis of endometriosis in women with the anticipation of infertility affects each aspect of a woman's life. Therefore, incorporating the assessment of mental health in patient with endometriosis is essential to provide quality, holistic, patient care.

## **CHAPTER V**

### **Discussion**

The purpose of this study was to assess the quality of life of women with endometriosis as it relates to infertility from the perspectives of the health care provider. The goal of this study was to encourage health care providers to incorporate the psychosocial aspect of care into their care for women diagnosed with endometriosis. Some physicians believe it is not their responsibility to acknowledge the emotional aspect of endometriosis, while others neglect to address it all. Holistic care is a vital component of patient care and should be equally integrated into patient care by all member of the health care team and not dismissed to the idea that is not listed on you job description. The psychosocial health of women diagnosed with endometriosis should be assessed and meaningfully addressed by health care professionals.

### **Implications of Findings**

The data collected in the study revealed the influence endometriosis has in a woman's everyday life. From work to relationships to mental status, endometriosis plays a huge role in the lives of women diagnosed with endometriosis and their partners. More than half of the participants believed there is a correlation between endometriosis and mental health issues. Most health care providers stated that due to the pain and infertility issues associated with endometriosis, most women suffer from anxiety and depression. Anxiety develops from the uncertainty of being able to conceive a child. Depression may be related to infertility issues and the physical pain that may develop because of endometriosis. Health care providers stated that due to the unbearable pain that may be expressed in women with endometriosis, women may also miss several days of work and

as a result, miss out on career opportunities, such as advancement. Pain could also affect psychosocial health by causing the client to cancel plans with friends and family.

Infertility related to endometriosis also influences how a woman views themselves. Some participants stated that due to their decreased chance of having a child, women may see themselves as less of a woman and feel isolated from others. Society often associates women with childbirth. So, when this role is threatened, it can cause women to lose their self-esteem and degrade their value. One participant stated the need to have a successful pregnancy can cause women to submerge their relationship into assisted reproductive technology such as intrauterine fertility (IVF) and allow it to consume their relationship and destroy their intimacy. Each health care provider stated that endometriosis has a major impact on women's everyday lives, mental health, and relationships.

All the health care providers who participated in the study constantly referenced mental health as an area associated with infertility due to endometriosis and stated the health care provider is responsible for addressing the psychosocial aspect of the illness, while more than 50% of respondents believe the client themselves are also responsible. Mental health can be impacted by infertility related endometriosis in many ways. Depression, anxiety, and your perceived body image all influence the ones everyday life. Tackling the mental issue along with the physical ailment can allow the client to cope both physically and mentally.

### **Application to Theoretical/Conceptual Framework**

Applying the Theory of Human Caring by Jean Watson allows health care providers to see the person as a whole. It encourages health care professionals to show purposeful gestures, meaningful actions to allow the client to feel valued. The Theory of Human Caring by Jean Watson also encourages the client to uplift themselves and admire the beauty within themselves. Participants frequently acknowledged the poor self-image women with endometriosis may experience due to its associated to infertility. Applying the Theory of Human Caring to this research study and incorporating it into practice highlights the primary goal of health care, which is to provide clients with optimal, quality patient care that addresses all aspects of health (Wei & Watson, 2019).

### **Limitations**

The research study was limited by the small sample size, lack of a diverse population, and generalization of the survey questions. The research study could have been strengthened by including the family planning departments of all the public health departments in the region. The research study was also limited to the number of prior research studies that examined the quality of life of women with endometriosis and its' relation to infertility from the perspective of health care providers.

### **Implications for Nursing**

The following are nursing implications derived from this study:

- Assess the client's mental health
- Discuss the emotional effects women diagnosed with endometriosis may experience

- Provide holistic patient care by addressing the physical and mental impact endometriosis has on a client's life
- Include the clients' partner in the mental health assessment to discuss the strains endometriosis may have on their relationship

Registered Nurses also have a responsibility to ensure that all the client's needs are addressed, both physically and mentally. Acknowledging the mental effect endometriosis can have on a client and applying the Theory of Human Caring into client care is an integral part of patient-centered care and human caring.

### **Recommendations**

Endometriosis is an illness that is still being examined; therefore, further research should be conducted regarding the psychosocial aspect of endometriosis from the perspective of health care providers, women who have been diagnosed with endometriosis, and partners to increase awareness of the vast emotions that accompany the illness. Also examining the extent to which clients are responsible for their own mental health at the initial diagnosis of the illness. Most participants held both the health care provider and the client themselves responsible for their mental health in relation to endometriosis. These concepts should be examined further. Increasing the sample size and the population sample is also recommended to strengthen the study. Would the results vary if there was an equal number of female and male health care providers? Diversifying the population and inviting participants to participate in the research study in different states should also be evaluated.

## **Conclusion**

The lack of understanding of endometriosis can cause many people to disregard or fail to consider how it may affect women emotionally. Even health care providers have stated that they neglect to address the psychosocial aspect of endometriosis, only focusing on the physical characteristics of the illness. This is not a representation of holistic care, which is the basis of health care. Women diagnosed with endometriosis suffer from depression, poor self-reflection, and anxiety due to the possibility of not being able to bare children. Though this is a mental health concern, it can still affect the client's quality of life and relationship. Women are often viewed in society as a mother whose purpose is to carry a child. Acknowledging the emotional heart break of being diagnosed with endometriosis is as important as discussing treatment options for the physical pain and discomfort.

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## Appendix

### **E-Mail to be Sent to Potential Participants with Informed Consent**

**Subject:** Invitation to Participate in the Study: Health Care Providers' Perspectives of a Woman's Quality of Life Facing Endometriosis and Infertility

My name is Bridget Ford and I am in the graduate school at Gardner-Webb University Hunt School of Nursing, pursuing a Master of Science in Nursing (MSN) degree. My thesis title is "Health Care Provider's Perspectives of a Woman's Quality of Life Facing Endometriosis and Infertility." I am emailing to request your participation in a qualitative research study where you will complete a brief survey. The survey can be accessed via the link to Survey Planet at the end of the e-mail below. Health care providers of patients with endometriosis have been chosen to participate in this four-question qualitative survey to examine the health care provider's perspective of how infertility and a diagnosis of endometriosis impact a woman's quality of life.

Title of Study:

Health Care Provider's Perspectives of a Woman's Quality of Life Facing Endometriosis and Infertility

Researcher:

Bridget Ford, BSN, RN

Graduate Nursing Student at Gardner-Webb University

#### **Purpose**

The purpose of this qualitative research study is to evaluate a health care provider's perspective of the quality of life of women with infertility related to endometriosis. Often the impact that endometriosis plays in a woman's life and relationship are rarely acknowledged. Endometriosis can not only affect a woman's reproductive system, but it also can decrease her self-esteem, which in turn can affect future and current relationship as well as her career. Examining the importance of assessing women's emotional and social health with the physical aspects of the illness are all imperative to provide quality patient care.

#### **Procedure**

##### **What you will do in the study:**

Participants will be asked to complete a four-question survey titled Caregiver Perspectives of a Woman's Quality of Life Facing Endometriosis and Infertility Survey, via Survey Planet, regarding their perception of women with infertility related to endometriosis via email. Each question is open-ended, allowing you to type your personal response.

**Time Required**

It is anticipated that the study will require no more than 30 minutes of your time.

**Voluntary Participation**

Participation in this qualitative study is voluntary. You have the right to withdraw from the research study prior to submitting your responses without penalty. The responses are completely anonymous; therefore, you cannot withdraw once you have submitted your survey. You also have the right to refuse to answer, or skip, any question(s) for any reason without penalty.

**Confidentiality**

No personal identification will be collected from participants. All data from the surveys will be organized on a Microsoft Excel spreadsheet by the researcher and stored on a flash drive which only the researcher will have access. At the completion of the study, the data will be given to the Hunt School of Nursing where it will be kept for three years then destroyed. The results of this research will be shared with the Hunt School of Nursing at Gardner-Webb University and uploaded to a GWU Dover Library electronic database. Results will also be reported to nursing administration of the participating facility in the Family Planning Services department.

**Data Linked with Identifying Information**

The information that you provide in the study will be anonymous with no identifiers collected.

**Anonymous Data**

Your data will be anonymous which means that no identifiable information will be collected nor linked to the data.

**Risks**

There is a potential risk that participants may experience discomfort with reflecting on personal experiences with endometriosis patients. If this occurs, please seek assistance from the employee health via human resources department. You also have the right to withdraw from the study prior to submitting your survey, without penalty.

**Benefits**

There are no direct benefits associated with participation in this study. The study may help to understand the importance of incorporating psychological care into the care plan for women experiencing infertility related to endometriosis.

**Payment**

You will receive no payment for participating in the study.

**Right to Withdraw From the Study**

You also have the right to withdraw from the study prior to submitting your survey.

**How to Withdraw from the Study**

If you want to withdraw from the study, you may close the survey browser at any time prior to submission. There is no penalty for withdrawing. Due to confidentiality measures, please note that you will not be able to withdraw from the study after your survey has been submitted.

**If you have questions about the study, contact the following individuals.**

Bridget Ford, BSN, RN  
Current Graduate Student  
Gardner-Webb University  
Boiling Springs, NC 28017  
803-236-2068  
[bgayle@gardner-webb.edu](mailto:bgayle@gardner-webb.edu)

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Boiling Springs, NC 28017  
704-406-2518  
[bnhudgins@gardner-webb.edu](mailto:bnhudgins@gardner-webb.edu)

**If the research design of the study necessitates that its full scope is not explained prior to participation, it will be explained to you after completion of the study. If you have concerns about your rights or how you are being treated, or if you have questions, want more information, or have suggestions, please contact the IRB Institutional Administrator listed below.**

Dr. Sydney K. Brown  
IRB Institutional Administrator  
Gardner-Webb University  
Boiling Springs, NC 28017  
Telephone: 704-406-3019  
Email: [skbrown@gardner-webb.edu](mailto:skbrown@gardner-webb.edu)

To access the survey, please use the following link:

<https://s.surveypal.com/WHDF2diSXx>

Please note that by clicking on this link and completing this survey, you are implying you consent.

The Gardner-Webb University Institutional Review Board (IRB) approved this study. Should you have any comments or questions, please feel free to contact me via e-mail at [bgayle@gardner-webb.edu](mailto:bgayle@gardner-webb.edu).

Your participation will be greatly appreciated and thank you for your time and cooperation!  
Sincerely,

Bridget Ford, BSN, RN