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“IT’S NOT CRAMPS... THAT’S NOT NORMAL”: A QUALITATIVE
STUDY ON ENDOMETRIOSIS DIAGNOSIS

A Thesis
Presented to
the Graduate School of
Clemson University

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
Communication, Technology, and Society

by
Kayla Craig
May 2020

Accepted by:
Dr. Travers Scott, Committee Chair
Dr. Kristen Okamoto
Prof. Leland Fecher

ABSTRACT

This is a qualitative study, regarding women with the chronic pain condition endometriosis, utilizing in-depth interviews. Endometriosis is a chronic pain condition in which the tissue of the uterus is found outside the uterine cavern. This tissue leads to many symptoms that can affect a woman's social, personal, and professional life. Guiding literature on the history of women's health, validation through diagnosis, patient-provider relationships, social support, and dialogism in health communication were used to inform this research. A narrative analysis approach was used to analyze the findings which consisted of four narratives: manifestations of pain, social support, patient-provider communication and what diagnosis means.

Keywords: endometriosis, diagnosis, dialogism, doctor-patient relationships, chronic pain, women's health, gender

DEDICATION

This thesis is dedicated to the women who, like me, are still seeking an endometriosis diagnosis. I know how hard it can be when it feels like no one believes you. If I have learned anything in this process, it is to never give up courage and to keep fighting for your voice to be heard, always.

ACKNOWLEDGMENTS

I would like to first acknowledge Dr. Angela Pratt, to whom I talked about my thesis at its conception. Had we not talked about her experience, I would have never interviewed other women about their experiences. Without her story, this project would have been completely different, and I don't know if I would have had the courage to keep seeking an endometriosis diagnosis myself. To the ten women who volunteered to participate in this study, I know how hard it was for us to talk about this, but I am so thankful for you. This would have been impossible without you. My thesis advisor, Dr. Travers Scott, for always being understanding, compassionate, and giving me grace, even when I missed a handful of deadlines because I was too stressed to even look at my thesis. My committee members, Dr. Kristen Okamoto and M.A. Leland Fecher, for always being enthusiastic and excited about my research. Lastly, I would like to thank my mom and dad, Jennifer and Cory Craig, for always encouraging me to pursue my interests and still loving me even when I didn't call them for a month and a half because I was "too stressed." Without all of you this project would not have been possible, thank you.

TABLE OF CONTENTS

	Page
TITLE PAGE	i
ABSTRACT.....	ii
DEDICATION.....	iii
ACKNOWLEDGMENTS	iv
CHAPTER	
I. INTRODUCTION	1
Personal Familiarity	2
Endometriosis	5
II. LITERATURE REVIEW	11
Historicizing Women’s Healthcare.....	11
Diagnosis.....	16
Pain	17
Patient-provider Relationships.....	19
Social Support.....	25
Dialogism in Health Communication	27
III. RESEARCH DESIGN AND METHODS	29
Qualitative Research	29
Interviewing	30
Recruiting Participants.....	33
Collecting Data	35
IV. PARTICIPANT NARRATIVES	37
Manifestations of Pain	38
Social Support.....	42
Patient-provider Communication.....	48
What Diagnosis Means	54
VI. DISCUSSION.....	59

Table of Contents (Continued)	Page
Implications.....	59
Limitations	63
Future Directions for Research	64
VII. CONCLUSION.....	67
APPENDICES	69
A: Interview Script.....	70
REFERENCES	71

CHAPTER ONE

INTRODUCTION

This is a qualitative research study concerning dialogism and communication between women and their healthcare providers during the diagnostic period of endometriosis. Semi-structured interviews and narrative analysis have been used to collect and analyze data for this project. The research questions that guided this project were: How do women narratively understand their diagnostic experience of endometriosis?

Endometriosis is a chronic pain disorder affecting approximately one in ten women. I used dialogism as a lens to help me understand my participants' experiences. Bakhtin (2010) describes dialogism as a three-way drama between, sender, receiver, and subject matter. I employed the narrative analysis approach to interpret the experiences and stories told by the women interviewed to see what narratives regarding dialogism and doctor-patient relationships emerged. Narrative analysis allowed me as a researcher to uncover experiences and stories from my participants. I had anticipated that the experiences and stories, when put together, would have the ability to answer my research questions in a way that a thematic or discourse analysis may not be able to do.

Because endometriosis is a disorder that regularly goes unnoticed, it was important to me as a researcher to understand the stories of those with the disorder. The methods I chose to complete this project—one-on-one interviews and narrative analysis—are those that I found best suited for my goals. This research project was approved by Clemson's Institutional Review Board in October 2019 and amended in January 2020 to update recruiting methods.

Personal Familiarity

Many qualitative researchers value the conception of “trustworthiness” (Cousin, 2010). In order to achieve a level of trustworthiness, such researchers will address their own familiarity with a topic in their research (Cousin, 2010). For this research project, developing trustworthiness with my audience and with my participants was very important. In order to do this, there are some experiences of my own that I have shared. I first heard about endometriosis when I was a teenager; today I am unsure if it was when I first got my period or after some time. When I was fourteen, I started getting my period, and with it came debilitating pain that left me reliant on over-the-counter painkillers every month. I needed to take some kind of painkiller whenever my period came just so I could go to school or participate in soccer and track practices. Some days I needed them just to get out of bed.

I was the oldest child in the family on both sides, which left as the only women I could talk to in my family about my period my mom, my aunt, and my grandmothers. I did talk to girls in my class, but I lived in rural America. There were only 13 other girls to talk to, and it did not seem like many of the girls that had their periods experienced the same level of pain as I did. So, naturally, I talked to my physician about it. I told her how much pain I experienced every month and all but begged her for some help. She told me that it was actually quite normal to experience pain during our periods; it was just something women had to go through. As she was much older than me, and my physician, I assumed she was right. She was the expert, so I went on birth control pills.

Eventually my mom started to get a little worried about the pain I was still experiencing, even on hormonal birth control. To this day, I do not know if she went to my grandmothers and asked for advice or if she just knew this, but she told me my grandmother on my father's side had endometriosis. My grandmother only had three sons, so if Stefansson, et al. (2002) and Dos Reis, et al. (1999) are correct, and endometriosis is genetically inherited, there were no women in the generation above me, or relatively close to my age, on that side of the family that could have had it or talked with me about it.

Going to the doctor has always caused me great anxiety, but, when I was younger, I did not have much control over whether or not I went. This apprehension of being in hospitals has stuck with me, even at twenty-four. The last time I saw a physician for a regular check-up, and explained my symptoms to them, was two years ago. I remember the anxiety of sitting in the hospital gown, with my back exposed, on the cold bed, waiting for my doctor to come in. I had a chore list of issues I wanted to talk with her about, and I was sure to write them all down in a note on my phone, because I knew I forgot things a lot when I was talking to my physician. I told her about all of the problems, and it felt as if each one was swept under the rug. At the time, I had severe back pain. I wasn't able to bend over to put my socks, shoes, pants, or underwear on without being in excruciating pain. My roommate had to tie my shoes sometimes because I couldn't bend over for long enough to do it. The physician I was seeing told me that it didn't seem like it was that serious and would probably figure itself out. The same day, I told her about a problem I had been experiencing for about seven years, she suggested a

treatment option. When I told her I had tried it a few times and it hadn't worked, she told me I should try again. Finally, I told her about the pain I experienced during and around my periods, even though I was on birth control. My physician told me it was normal to experience that pain, and that if I wanted more information about it, I should go to the health center at my college. In that moment, I felt both angry and helpless. I haven't been to see anyone, aside from getting checked for a cold at my graduate institution's health center and my regular appointments with my dentist, since.

It has been 10 years since I have started experiencing some of the symptoms of endometriosis and expressing them to my doctors. However, I have never been diagnosed with endometriosis. I have had three different birth control prescriptions in this timeframe, a method of treatment for endometriosis among other things, and still experience pain flare ups in my back and abdominal area that leave me doubled over in pain. Recently, I took a short break from the birth control that had stopped me from getting my period for nearly a year. During this, I experienced pain in my lower back and abdominal area that left me dizzy and disoriented. This painful experience will typically happen when I am sitting down or driving. My decision to do this research for my thesis came in the second semester of my masters degree when I was taking a health communication course. Students were encouraged to pick a gendered topic for our research paper. That project helped me gather articles and information for my literature review for this project, in addition to a better idea of exactly what I wanted to take a look at for my thesis.

I originally intended to look at the online communities that women with endometriosis are a part of as a means of receiving support. However, after a woman that had been diagnosed with endometriosis and had a full hysterectomy shared her experience with me in a casual conversation, I decided that speaking to the women who experience endometriosis and everything that comes with it would be more impactful and important work.

Endometriosis

The discussion of endometriosis begins in the late nineteenth century (Benagiano, Brosens, & Lippi, 2014). This was when people began describing the symptoms of the disease in literature. The people who were writing about endometriosis at this time did not refer to it specifically as “endometriosis.” However, they did note many characteristics in their writing that led researchers Benagiano, Brosens, and Lippi (2014) to believe they were writing about endometriosis. They came to this conclusion due to the descriptions of cyclic pain during menstruation, records of endometrioma being described as “haematomas of the ovary” or “chocolate cysts,” and mentions of an “ovary containing uterine mucosa” throughout records published in 1899 (p. 1). To reach these findings, researchers employed two methods: scouring ancient literature for descriptions of the symptoms associated with the disorder and identifying researchers who had described features of which we associate with endometriosis in various forms.

Today, endometriosis is understood as a gynecological disorder in which uterine tissue grows outside of the uterine cavity. This disorder is estrogen-dependent and typically associated with the cyclic nature of menstrual pain (Adamson, Kennedy, &

Hummelshoj, 2010; Ballard, Lowton, & Wright, 2006; Hsu, Khachikyan, & Stratton, 2010; Krebs & Schoenbauer, 2019; Rao, Siddiq, Qadi, Sarfraz, & Rana, 2019).

Menstruation typically begins between ages 11 and 14 and continues until approximately age 51 (Zafar, Sadeeqa, Latif & Afzal, 2017). There are four basic stages of the menstrual cycle, all of which can cause endometriosis flare ups, depending on the patient. The four basic stages of the menstrual cycle are menstruation, the follicular stage, ovulation, and the luteal stage (Zafar, et al., 2017). Menstruation is the stage most people are familiar with; this is when the thickened outer layer of the uterus sheds itself through the vagina, most commonly referred to as a woman's period. During the menstrual cycle, women's hormones increase and decrease depending on the stage. This change in hormone level is what causes the uterine lining to thicken and eventually shed.

Many common symptoms of endometriosis include, but are not limited to, pain during menstruation, pain during ovulation, pain during and after intercourse, pain during bowel movements or urination, back pain that worsens during menstruation, excessive bleeding during or between periods, infertility, fatigue, diarrhea, constipation, bloating, and nausea (Hsu, et al., 2010; Rao, et al., 2019; Wellbery, 1999). Severe endometriosis is associated with infertility due to the destructive nature of the disorder that can result in anatomical distortion of pelvic organs (Rao, et al., 2019). Some women do not experience any of the painful symptoms that are associated with endometriosis and instead experience infertility as their only symptom associated with the disorder. This can lead to endometriosis going undetected until women try to get pregnant (Hsu, et al., 2010). Symptoms associated with endometriosis can be incredibly debilitating, leading to

extended absences in women's careers and education (Krebs & Schoenbauer 2019). The symptoms also have a strong impact on women's social and mental well-being (Adamson, et al., 2010; Krebs & Schoenbauer, 2019).

Evidence has led researchers to believe that endometriosis has familial tendencies (Bischoff & Simpson, 2004; Stefansson, et al., 2002). This evidence comes from reports of familial clustering and increased diagnosis of endometriosis among first degree relatives (Stefansson, et al., 2002). The risk of first degree family members developing endometriosis when their relatives have it has been reported to be four-to-eight times more than the general population (Stefansson, et al., 2002). Additionally, women with siblings or parents with endometriosis are more likely to have severe endometriosis rather than mild or moderate endometriosis (Bischoff & Simpson, 2004). Family and twin studies have shown that many kinds of disorders have the ability to be inherited through one's family; endometriosis is no different in this sense than diseases such as diabetes (Vigano, Somigliana, Vignali, Busacca, & Di Blasio, 2007).

As with many diseases and disorders, the diagnosis process of endometriosis begins when the patient discloses their symptoms to their physicians. Women are typically between the ages of 25 and 29 when they are diagnosed with endometriosis. However, women can start exhibiting signs of the disease as early as puberty (Wellbery, 1999). Much of the reason that there is such a long diagnostic period for endometriosis is that there is simply a lack of understanding surrounding the disorder (Hsu, et al., 2010). This lack of understanding seems to stem from the immense spectrum of symptom severity. In addition, the correlation between lesions and pain symptoms being

misunderstood plays a role in diagnostic time as well (Hsu, et al., 2010). Women have been noted to experience both pain and infertility, women can experience any number of symptoms at any level of severity. In some instances, diagnosis can take even longer if women do not experience physical pain but, instead, experience only infertility as a symptom (Wellbery, 1999). Similarly, in some instances, the stage of endometriosis that shows up on diagnostic laparoscopies, a method of diagnosis, correlates poorly with the extent and severity of pain (Hsu, et al., 2011).

A diagnostic laparoscopy is when a small incision is made in the abdominal cavity to visually inspect the area with a small camera (Laparoscope, n.d.), the procedure is considered minimally invasive to patients (Barreiro, et al., 2002). The diagnosis and treatment of many gynecological diseases are performed using laparoscopic surgery (Wang, et al., 2001). In fact, laparoscopy has, for many years, been considered the gold standard for diagnosing women with endometriosis (Hogg & Vyas, 2017; Hsu, et al., 2011; Krebs & Schoenbauer, 2019; Wang, P. H., et al., 2001). Advanced laparoscopic skills are required to diagnose the disorder properly; these skills are generally acquired through fellowship-level training (Hogg & Vyas, 2017; Leonardi, Martin, Reid, Blanchette, & Condous, 2019; Rao, et al., 2019). Additionally, the accuracy of the diagnosis is partially dependent on the severity of the disease, as physicians are looking for, and must be able to see, the endometrioma growths throughout the cavity (Rao, et al., 2019).

Currently, there is no cure for endometriosis (Krebs & Schoenbauer, 2019). However, some women opt for the surgical extraction of the excess endometrial tissue.

Laparoscopic procedures can also be used as a means of treatment, this method is referred to as an operative laparoscopy (Brown & Farquhar, 2014; Wang, et al., 2001). The treatment has been proven to reduce overall pain and increase live-birth or ongoing pregnancy rates in women with mild endometriosis (Centini, Afors, Murtada, Argay, Lazzeri, Akladios, ... & Wattiez, 2016). While there may be concerns about undergoing a surgical procedure, the risks associated with laparoscopic surgery are minimal (Wang, et al., 2001).

Surgical intervention is not always possible, as the financial burden of this treatment can turn some of those suffering away (Hsu, et al., 2011). It is suggested that endometriosis has an impact of 22 billion US dollars on the economy in the United States due to lost working time and healthcare costs related to the disease (Leonardi, et al., 2019). The surgical procedure, of both the diagnosis and treatment of endometriosis, have been referenced as major contributors to the financial burden of the disorder, both on the individual women with the disorder and the US economy (Hsu, et al., 2011; Leonardi, et al., 2019).

Approximately 10 percent of women of childbearing age are affected by endometriosis (Adamson, et al., 2010). This makes endometriosis one of the most common gynecological disorders, affecting approximately 176 million women in the world (Adamson, et al., 2010; Krebs & Schoenbauer 2019). According to the US census, as of 2017, there were approximately 76,791,565 women of childbearing age, between the ages of 15 and 50, in the United States (U.S. Census Bureau, 2017). Therefore, 7.7 million women in the United States can be estimated to be affected by endometriosis in

2017 (U.S. Census Bureau, 2017). Caucasian and Asian populations are more likely to be affected by endometriosis than Hispanic and black populations (Rao, 2019). Only a fraction of these women will ever be diagnosed (Adamson, et al., 2010). Presently, women suffer from endometriosis-related pain for approximately 10 years before being diagnosed by their gynecologists with endometriosis (Ballard, et al., 2006; Krebs & Schoenbauer, 2019). While there have been many advances in medicine, endometriosis remains a disorder that receives inadequate attention from the medical community (Krebs & Schoenbauer, 2019).

CHAPTER TWO

LITERATURE REVIEW

Literature on the history of women's healthcare in the West, patient-provider relationships, social support, and dialogism informed this research project. This literature has been used as a means of providing a better understanding for the data collected for this project as well as informing the discussion portion of this essay.

Historicizing Women's Healthcare

Historically, there has been a lack of study of the female body. When the female body was being studied medically or scientifically, it was by men trying to fit their agendas, as women were not allowed in medical and scientific fields (Schiebinger, 1986). It is important to recognize that the men making these discoveries and advancements in medicine were white men, who used medicine and biology to dictate where women and other minorities were in the social hierarchies. Ehrenreich & English (1979) describe the way in which women and other minorities were talked about by those in science:

This was the intellectual framework with which nineteenth-century biologists approached the Woman Questions: everyone must have an assigned place in the natural scheme of things. Attempts to get out of this place are unnatural and in fact, diseased. By the eighteen sixties, natural scientists could pinpoint woman's place on the evolutionary ladder with some precision—she was at the level of the Negro. (p.107)

Women were studied as anomalies, wrong and lesser than the white men studying them; all they were good for was their childrearing ability (Reed, 1999; Schiebinger, 1986). It took until the eighteenth century for European scientists to even come up with drawings

of the female skeleton, and, when they did, they were inaccurate and, again, portrayed women as less intelligent and made for childrearing (Schiebinger, 1986). For example, in these depictions of the female skeletons, the heads were smaller, as women were seen as less intelligent and their hips were broad, as they must bear children. Additionally, the female skeleton has been compared to the delicate skeleton of an ostrich while the males' skeleton was compared to that of a horse, strong and sturdy. Throughout history, the male body has been studied as normal, whereas the female body has been regarded as abnormal (Reed, 1999), this assumption has negatively affected women's healthcare, even today.

The birth of obstetrics and gynecology has a very similar history (Lewis, n.d.). Obstetrics, the branch of medicine that encompasses childbirth and the care of women who give birth, naturally stemmed from midwifery. It was not until the seventeenth-century that European physicians began to transition the health of pregnant women and the process of pregnancy into a medical issue. Gynecology, as a field, dates back to Greco-Roman times, if not earlier. However, modern gynecology did not emerge until the early to middle nineteenth-century, due to the use of anesthesia and antiseptics, gynecological operations became feasible and safer (Lewis, n.d., Ward, 1936). It was in the nineteenth century that surgeon James Marion Sims begins practicing a variety of surgical operations on the ovaries and uteruses of enslaved women (Lewis, n.d.; Sartin, 2004; Ward, 1936). During Sims' experimental operations on slave women, he operated forty-two times on three patients, and twenty-one times on another (Ward, 1936). The issues surrounding the birth of gynecology at the hands of James Marion Sims is not just

a racial issue, but also a class issue (Sartin, 2004). Sims operated on women in the upper class with the use of anesthetics. However, the enslaved and poor Irish-American women he operated on did not receive this luxury. The birth of gynecology has framed the field in a very negative way: the advancement of physicians is what was important, not the health of women (Schiebinger, 1986). In other words, the field of gynecology in and of itself was established as a means to placate male curiosity, not as a means of helping women (Schiebinger, 1986). For example, when Sims left the South and headed to New York, he was faced with allegations of mistreating lower class, Irish-American women who visited his Woman's Hospital. Sartin (2004) recounts this visit:

He found himself in a similar situation in New York, as his Woman's Hospital catered to destitute Irish immigrant women, whose inferior social status did not allow for them to decline questionable treatments...He was criticized directly for unethical experimentation by his colleagues and the hospital administration during the acrimonious debates of the 1870s. (p.6)

Scenarios like this encourage and relate directly to a neglect to understand the diseases and disorders that plague women.

The practices associated with women's health are not the only issue. The language that has been used to describe women's reproductive health throughout history has been demeaning and counterproductive as well. The most obvious place to start is the use of the term "hysteria." There was a time when "hysteria," derived from the word "hysterika," the Greek word for uterus (SciShow, 2018), was what women were diagnosed with when doctors did not know what was ailing them (McVean, 2017; Morris

& Donohoe, 2004). Hysteria was a diagnosable mental disorder until 1980 and can be traced back to the times of the ancient Egyptians (McVean, 2017; Morris & Donohoe, 2004). It was thought that the uterus affected the body in such a way that it could cause a diverse set of ill effects, which is why women were diagnosed with it when their physicians did not have the answers for them (McVean, 2017; Morris & Donohoe, 2004). The uterus was blamed for conditions such as anxiety, insomnia, depression, irritability, and fainting (McVean, 2017). Throughout history, the reasons women were diagnosed with hysteria have changed. However, those being diagnosed with the disorder never did, it was only ever women (Morris & Donohoe, 2004). While women are no longer being diagnosed with hysteria, women who display symptoms of endometriosis are often misdiagnosed with diseases such as pelvic inflammatory disease or irritable bowel syndrome (Hsu, et al., 2010).

We can see the remnants of hysteria as a mental condition still plaguing the treatment and diagnosis of women's health issues. This is particularly salient when it comes to endometriosis, as women are constantly left undiagnosed, and, in some cases, misdiagnosed (Krebs & Schoenbauer, 2019). The lack of proper help and proper healthcare for women is not at all a new phenomenon (Young, Fisher, & Kirkman, 2018).

Second-wave feminist activism and scholarship in the 1960s-70s encouraged critical analysis of the term hysteria from a female perspective, something that had ultimately never been done, as men had controlled healthcare for the majority of human history (Morris & Donnohoe, 2004). Today, hysteria is no longer a diagnosable disorder. However, many women with endometriosis are beginning to be diagnosed with

“somatization,” the modern-day version of hysteria (Krebs & Schoenbauer, 2019).

Somatization is a generalizable term that is best defined as the “psychological factors that cause symptoms of a disease without apparent physical pathology” (Krebs & Schoenbauer, 2019, p. 2). The real difference between somatization and hysteria is that there are men who are diagnosed with somatization as well; this is not something that is just plaguing women (Wool & Barsky, 1994).

Misdiagnosis and abhorrent use of language have been detrimental to women with endometriosis, as they create a major barrier to being diagnosed with an actual gynecological disorder (Krebs & Schoenbauer, 2019). The diagnosis of somatization leads to women being referred to psychologists and psychiatrists, who have no experience with diagnosing endometriosis, instead of a gynecology specialist who may have experience with endometriosis. The proper use of language is the first step in helping women with endometriosis, and other chronic pain disorders, get the help they need, diagnosing women with disorders such as hysteria and somatization does a disservice to both the medical field and the women themselves.

Endometriosis has piqued the interest of many feminist scholars, as it is a meeting point of knowledge, gender, and power (Young, Fisher, & Kirkman, 2018). Many studies involving endometriosis take on a feminist approach in the research design (Denny, 2009; Huntington & Glimour, 2005). This framework allows researchers to assess the merit of the project through the women that are their participants (Huntington & Gilmour, 2005). Additionally, the pain experienced with endometriosis is, in and of itself, gendered

(Denny, 2009). Because of the cyclic nature of endometriosis, the pain is described and understood as an aspect of femininity that women must live through.

Diagnosis

For women with endometriosis, the importance of a medical diagnosis cannot be stressed enough. A diagnosis helps many women accept their pain as a genuine experience that is different, or abnormal (Denny, 2009), rather than something that is just part of being a woman. Chronic pain is frequently associated with physical, emotional, and social limitations. Because endometriosis is related to the cyclic nature of the menstrual cycle, women may be less inclined to seek out help (Clarke, et al., 2014; Denny, 2009). Additionally, some women may be unaware of the treatment options for them, thus bringing them to the conclusion that it does not matter if they seek help (Clarke, et al., 2014).

For many with chronic pain conditions, a diagnosis is sought as a means of bringing validation to the sufferer (Clarke, et al., 2014). Research supports the notion that women with chronic pain disorders experience invalidation from their peers (Nguyen, et al., 2012). Past studies have shown that women experience distress resulting from others that invalidate women's chronic pain experiences (Nguyen, Ecklund, MacLehose, Veasley, & Harlow, 2012). This distress can lead to social isolation of individuals with endometriosis and other chronic pain conditions. Women with chronic pain disorders will typically perceive that others challenge the truth of their experiences with chronic pain conditions such as endometriosis.

More specifically, some women will turn to their physicians as a form of validation. Physicians are considered an external source of validation, frequent visits to physicians resulting in no diagnosis or a misdiagnosis can underscore feelings of invalidation (Nguyen, et al., 2012). Many women with endometriosis visit multiple doctors prior to getting a diagnosis of endometriosis (Shadbolt, Parker, Orthia, 2013). This may lead to greater feelings of invalidity and isolation (Nguyen, et al., 2012). The apprehension to communicate with doctors after repeatedly being invalidated during the diagnostic process of endometriosis likely contributes to diagnosis times as some women may not feel comfortable expressing their symptoms to their future physicians.

Pain

When patients are describing their level of pain to their physicians, they must rely on verbal descriptors in order to do so (Kenny, Trevorrow, Heard, & Faunce, 2006). In order for patients to communicate this pain, they need to have the language to do so (Kenny, et al., 2006). The English language has plenty of terms to use when trying to describe pain, but in some instances patients are unable to assign a descriptor to our pain or patients and physicians have a different understanding of the term used (Kenny, et al., 2006; Smith, 2006). This means that a patients attempt to communicate their pain to their physician may be unsuccessful if they do not assign the same meaning to the descriptors used (Kenny, et al., 2006).

Scarry (1985) suggests that there are not many written narratives provided about pain, which leads to miscommunication and misunderstandings when patients try to describe their pain to physicians. Scarry (1985) notes that there are many ways to

describe different kinds of love, but an incredibly small number of narratives that depict pain. This is translated into describing pain to physicians, Scarry (1985) suggest that pain carries with it an aspect of unsharability, language does not provide people with the privilege to describe pain to others.

Kenny, et al. (2006) asked participants to use pain descriptors to describe the worst pain they had ever experienced and to rank it from one to ten. Following this they provided the participants with other pain descriptors and asked them to organize them on a scale of one to ten (Kenny, et al., 2006). Researchers found that participants did not share an understood meaning of the descriptors they were asked to rank. Researchers suggested that this means there cannot be a scale that transforms verbal descriptors into numerical indications of pain until there is a commonly understood meaning of these descriptors.

Scarry (1985) suggests that those experiencing pain “effortlessly grasp” (p. 4) what the pain they are experiencing is, however the person they are describing it to will never be able to effortlessly grasp the pain. She states that for the person who is outside of the sufferer’s body, the only effortless thing is simply not understanding and remaining unaware of what the sufferer is experiencing. This effortless inability to understand can lead to those outside of the sufferer’s body doubting the pain they are experiencing.

As endometriosis is an invisible disease, it makes it exceptionally hard for those suffering to find the language that proves that they are experiencing pain. As they are unable to prove this pain physically, they are entirely reliant on language, which has proven to be unreliable (Kenny, et al., 2006; Scarry, 1985). This can mean that their

friends, family, coworkers, and physicians doubt their pain, which likely leads to the feelings of invalidity mentioned previously (Nguyen, et al., 2012).

Patient-provider Relationships

The doctor-patient relationship has been a topic of debate since Hippocrates and has appeared in over 8,000 articles, in fields such as philosophy, sociology, communication, and psychology (Goold & Lipkin, 1999; Hellin, 2002; Kaba & Sooriakumaran, 2007). Throughout history, the doctor-patient relationship has primarily been a patient seeking medical assistance, and a physician making decisions with which the patient silently complies (Kaba & Sooriakumaran, 2007). This model of doctor-patient relationship has been referred to as “paternalistic” (Kaba & Sooriakumaran, 2007; Hellin, 2002), as the doctor was the one holding power over the patient and making decisions of what the patient must do as a means of “getting better.”

The paternalistic methods of medical intervention can be traced back to the Hippocratic doctors of ancient times (Hellin, 2002; Kaba & Sooriakumaran, 2007). Doctors felt it was their obligation to heal their patients of their pain and illness, even if this meant that they were doing this despite their patients’ desires, and in some cases, even against their will. Doctors were taking on similar roles to parents, ultimately because it was a common belief that an ill person was both a biological and moral invalid (Adler & Hammett, 1973; Hellin, 2002). Similarly, patients were expected to take on roles of children, becoming passive as a means of getting treatment (Adler & Hammett, 1973; Hellin, 2002). Classic texts refer to pain and pleasure as immoral counselors, that is, illnesses elucidate pain, and pain clouds judgement and decision-making skills (Hellin,

2002). Hippocratic physicians believed their patients were in need of, not only intervention to alleviate their patients' physical illness, but also psychological interventions (Hellin, 2002).

Over the past decades, there have been many changes regarding the relationship between physicians and their patients (Hellin, 2002; Kaba & Sooriakumaran, 2007; Steinhart, 2002). Hellin (2002) claims that these changes are due to three factors: "(1) the increase in patients' rights and the patients' emancipation movement, (2) the ethical issues raised by technological advances in medicine, and (3) the influence of economics and healthcare policies" (p. 450). This specific change began in 1969 when the first code of patients' rights was written explicitly defining that adult patients can, and must, make the decisions that govern their own bodies (Hellin, 2002; Steinhart, 2002). Steinhart (2002) points to both the women's movement and the civil rights movement as movements that helped push for better healthcare services, including better patient-provider relationships. Additionally, the publication of the *Belmont Report* in 1978, which outlined the basic ethical principles that should be taken into consideration when researching human subjects, further encouraged a change in patient-provider relationships (Sims, 2010; Steinhart, 2002). After this shift in healthcare, it was harder for physicians to establish paternalistic roles over their patients, especially with the implementation of informed consent (Hellin, 2002). Here, the physician has the information, but the patient, ideally, has the power to allow the physician to move forward with treatment or not.

In this newly defined relationship, it was the physician's responsibility to help give the patient agency in their illnesses, rather than take it away (Hellin, 2002; Steinhart,

2002). Hellin (2002) argues that, while this movement was towards a more balanced relationship between physicians and their patients, it also clouded the responsibilities of healthcare workers. Do healthcare workers engage in risk-taking to benefit their patients, or do they play it safe? Debates regarding the obligation to treat contagious patients and the rights of healthcare workers to avoid serious health risks rose from this shift in power (Hellin, 2002; Steinhart, 2002). For example, during the HIV crisis, some healthcare workers refused to treat HIV-positive patients. The epidemic “immobilized physicians and patients alike” (Steinhart, 2002, p.442). Because their physicians were refusing to help, patients lacked basic scientific knowledge and treatment of the infection (Hellin, 2002; Steinhart, 2002). Hellin (2002) argues that it is the ethical obligation of healthcare workers to give medical attention and assistance to all patients, regardless of risk. Because healthcare workers voluntarily chose their careers, they established a binding moral obligation towards the general public to help them. In an ideal world, a physician must maintain:

total commitment to the patients’ care, complete availability, a noncritical attitude towards lifestyles and value systems that can be very different from their own...[and] most importantly, a consideration for the patients’ best interests based on the patients’, not the physician’s, own values.

(Hellin, 2002, p.451)

Physicians’ inability to completely commit to their patients’ needs can be detrimental to these patients and the health of entire populations (Steinhart, 2002).

Unfortunately, the desire for an equally balanced relationship is not always attainable, as doctor-patient relationships are still defined by power (Hellin, 2002; Ishikawa, Hashimoto, & Kiuchi, 2013; Kaba & Sooriakumaran, 2007). In this relationship today, the physician still holds the majority of this power, maintaining the original top-down power dynamic. This means that the relationship remains asymmetrical and imbalanced. Szasz and Hollender (1956) argue that it is impossible to get away from the power dynamic of the doctor-patient relationship. The patient is ill and seeks out the physician because the physician has more knowledge about what may be happening inside the patient's body. The power in this relationship can lead to a disturbance in communication; physicians may fall into the trap of taking on a dominant role, leading to mistrust from their patients (Goold & Lipkin, 1999; Ting-Toomey & Dorjee, 2015; Wissow, Roter, Crain, Kercsmar, Weiss, Mitchell, & Mohr, 1998). If patients feel that their physicians are taking on a dominant role, they can feel as if their physician is being condescending, thus disrupting the relationship between the patient and their physician, and potentially disrupting the patient's ability to disclose their symptoms to their physician (Goold & Lipkin, 1999; Ting-Toomey & Dorjee, 2015; Wissow, et al., 1998).

During a basic visit to the doctor, the patient's physician must communicate with their patients effectively. As a means of doing this, the physician engages in the medical interview, which has three specific functions (Goold & Lipkin, 1999; Suchman, Markakis, Beckman, & Frankel, 1997). The functions of the medical interview are gathering information, developing and maintaining a therapeutic relationship, and communicating information (Goold & Lipkin, 1999; Suchman, et al., 1997). If a patient is

anxious, they will not be able to understand the information their physician is communicating to them. If a patient has no trust in their physician, they are less likely to disclose information well (Goold & Lipkin, 1999; Steinhart, 2002; Suchman, et al., 1997). All three of these functions happen in unison and determine the relationship between the patient and their physician. The relationship between the physician and the patient relates directly to the satisfaction of the patient regarding their encounter. There have been advancements in the medical field that allow for patients to utilize apps and websites to help understand the disorders and diseases that ail them. However, patients and their physicians must still interact as a means of effective healthcare (Krebs & Schoenbauer, 2019). Medical decision-making is not solely based on medical knowledge. It is not necessarily always objective. Like many communicative interactions, it is a social event, physicians must understand their patients' needs and wants. For endometriosis patients, their physicians must understand the role of communication in medicine. This is particularly salient regarding diagnostic testing, such as a laparoscopy. Physicians must be willing and able to listen to the concerns of these women and to take them seriously. Krebs and Schoenbauer (2019) argue that there has been a devaluation of communication in the medical field, specifically regarding women's medical concerns. Again, the systems of power that are working in doctor-patient relationships are culpable for this devaluation. This devaluation is cited as one of the most significant barriers to the diagnosis of endometriosis.

It may not be so obvious that just being a woman can affect one's doctor-patient relationship. Interactions in medicine are deeply rooted in social, cultural, economic,

political, and institutional contexts (Ferguson & Candib, 2002; Krebs & Schoenbauer, 2019; Johnson, Roter, Powe, & Cooper, 2004). The experience of non-white or non-male patients in healthcare can be much different from their white-male peers. These groups have a much harder time when it comes to care, screening, diagnostic testing, and treatment, and they have higher rates of morbidity and mortality. One reason for this is simply the way medical professionals, even female medical professionals, communicate with women and people of color. The language that is used in the meetings between these groups and their physicians are reminiscent of the paternalistic medical practices of the past (Krebs & Schoenbauer, 2019). To solve some of these issues, effective communication must be implemented, starting with physicians.

Effective communication in the patient-provider relationship requires positive cooperation from both patient and provider (Farzadnia & Giles, 2015). To reach this cooperation, physicians must be cognizant of the language they are using and ensure that they are not communicating condescendingly (Goold & Lipkin, 1999; Ting-Toomey & Dorjee, 2015; Wissow, et al., 1998). Understanding the roles of language in assessing patients' health, and in healthcare providers' diagnosis and treatment, is important to achieving effective communication in patient-provider relationships (Farzadnia & Giles, 2015). To achieve effective communication, it may require that doctors use language that classifies their patients as "sick." Classification of the human condition is something that we often find restrictive, yet it is innately human (Bowker & Starr, 1999). Classification can be seen as a positive thing in the case of endometriosis, as it explains the pain they are suffering from to the women with the disease, their friends, their family and their

colleagues (Ballard, Lowton, & Wright, 2006). The use of language is important for this process of classification, or diagnosis.

Social Support

Post-World-War-II gender roles led to a change in psychosocial life stages, a diversified set of women's needs when experiencing changes in their health (Sammarco, 2001). Women today are juggling marriage, children, careers, and degrees. Some women may be juggling all, but there is a certain understanding that women are able to do more than ever before, socially speaking. Endometriosis, as previously mentioned, effects all arenas of a woman's life because of the symptoms associated with it. Because of this, the relationships and tasks required to complete them may be harder to accomplish (Krebs & Schoenbauer, 2019; Sammarco, 2001). This will likely lead many women to seek out social support.

Social support has been the focus of many research projects, especially in the arena of health (Reblin & Uchino, 2008). Research has found that people who have extensive social networks of good quality have a decreased risk of mortality when compared to those who have low-quantity or low-quality social networks. In these studies, social support is conceptualized in several different ways. To clarify, the term social network refers to the amalgamation of social relationships in which an individual engages, and social support refers to one of the many functions of a person's social network (Heaney & Israel, 2008). Unlike other social functions, such as social undermining, social support is always perceived by the sender as a positive function in social networks. Whether or not it is received as positive is up to the receiver (Heaney &

Israel, 2008). Support can be broken down into different types, such as instrumental support, emotional support, informational support, and appraisal support (Heaney & Israel, 2008; Reblin & Uchino, 2008). Typically speaking, people tend to have a preference dependent upon their circumstances.

In a 2004 study on women with chronic pelvic pain, researchers found that the support women valued the most was emotional support and practical support that was sustained and matched “the chronicity of their pain” (Warwick, Joseph, Cordle, & Ashworth, 2004, p.127). Studies have found that social support provides a factor of protection for those seeking it, as it is capable of reducing the effects of stress on health (Heaney & Israel, 2008). Many people will look to their family and friends as a means of social support, as they are, typically speaking, the easiest and most accessible people to engage in communication and support (Warwick, et al., 2004).

Social support is perceived most positively by receivers when it matches the individuals specific support desires (Rising, Bol, Burke-Garcia, Rains, & Wright, 2017; Warwick, et al., 2004). When support received matches the support desired, the amount of stress the receiver is experiencing is likely to decrease (Rising et al., 2017). Because of the stigma surrounding gynecological health, some women may find it hard to seek social support from their close family and friends. This is where “weak-tie support” (Rising, et al., 2017, p. 470) comes in. Weak-tie support is when people seek the support of others with whom they are not particularly close. A good example of this is someone joining an online support group with thousands of people. People who prefer weak-tie social support

will likely benefit more from specific online communities that tackle the issues they are dealing with, such as endometriosis support groups on Facebook (Rising, et al., 2017).

In addition to the stigma surrounding gynecological disorders, much uncertainty surrounds endometriosis, especially regarding symptoms and treatment options for those with the disorder (Centini, et al., 2016). Because of this, women may find it additionally hard to seek social support.

Dialogism in Health Communication

In addition to the history of women's healthcare, patient-provider relationships, and social support, a key theoretical perspective for this project is dialogism. To understand dialogism, we must first understand dialogue. The ideal model of dialogue is two-way, symmetrical communication, which, in this case, would be between doctors and patients (Hether, 2014). In order to engage in dialogue, sender and receiver must, to some extent, merge their perspectives, in addition to still maintaining their individual unique perspectives (Baxter, 2004). Dialogue should be described in terms of "growing" or "composing" rather than in terms of "existing," as the process is more important to the fundamental understanding of dialogue than product is (Bakhtin, 2010; Linell, 2000).

Dialogism is a concept that was birthed by Russian philosopher of language Mikhail Bakhtin. While dialogism has meant and can mean many different things, and, in some instances, without reference to Bakhtin, many scholars understand the theoretical perspective through his work (de Man, 1983). His research traversed decades from the 1920s to the 1970s (Baxter, Hirokawa, Lowe, Nathan, & Pearce, 2004). Bakhtin critiques the monologic understanding of dialogue, and claims that all participants in a dialogue

are active voices (Baxter, 2004). Bakhtin claims that speech is experienced in two ways: the uniqueness of the language and the repeatability of the language (Bakhtin, 2010; Linell, 2000). He also insinuates that humans are able to understand meaning through dialogic interactions and, without these dialogic interactions, these meanings belong to only one soul (Bakhtin, 2010)

Linell (2000) summarizes dialogism as interaction, contexts, and linguistic-communicative constructions that occur throughout our lives. For this research project, the studied interactions are the conversations held between women and their physicians regarding their endometriosis symptoms. The concept of dialogism demands that discourse recognizes past and future interactions and the language being used in these interactions (Shepherd, 2011). In the context of endometriosis, it is important to note the language that was being employed in the past, both regarding women's health and throughout women's interactions with their physicians. Krebs and Schoenbauer's (2019) study on dialogism and diagnosis of endometriosis has been a guide for this research study.

Bakhtin (2010) describes dialogism as a performance between the subject, the receiver, and the sender. In regards to this study, we can understand the subject as the symptoms that women are describing to their physicians along with endometriosis. The receiver and sender should be understood as either the women I have interviewed for this project or as the physicians they are seeing about their symptoms. Bakhtin's (2010) conceptualization of dialogism and dialogue asserts that, in this study, both patient and provider are co-owners of information.

CHAPTER THREE

RESEARCH DESIGN AND METHODS

This research project consisted of ten in-depth interviews with women who had been diagnosed with endometriosis and those who believed that they had it. In order to reach my target population of participants, I utilized purposeful sampling alongside convenience and snowball recruiting. All interviews were held in person, via FaceTime, or over the phone. They were recorded on an app called Otter.ai which transcribed the interviews in real time. I later went through and fixed any errors that the preliminary transcripts may have had. Finally, I grouped similar narratives together, edited for clarity, and placed important quotes in this document.

Qualitative Research

This is a qualitative study that utilized in-depth interviews. The project received approval from Clemson's Institutional Review Board (IRB) on October 8, 2019, and was amended in January 2020.

Health research often uses conventional, quantitative research, and, in many instances, experimental research methods (Mays & Pope, 1995). Qualitative research in the health field is frequently criticized for lacking scientific rigor. However, while qualitative and quantitative data were fundamentally different, both are beginning to be recognized as capable of producing findings that are important to the health field. Over the last decade, qualitative methods have started to become more recognized as a means to collect significant data in social research (Nohl, 2010). Qualitative research methods allow researchers to collect rich, complex, and in some instances, unexpected data

(Sofaer, 1999). This method of research can highlight different experiences and interpretations of events through the disclosure of the participants in qualitative studies (Sofaer, 1999; Stuckey, 2013). Through this ability to highlight, researchers are able to give a voice to those who may be marginalized, or whose views and experiences are rarely heard. This is not to say that quantitative data does not collect rich and significant data. Some instances, like historical events, can be so unconventional that, when a researcher is finally able to quantify the events, they have changed or disappeared altogether. Qualitative analysis methods allow researchers to analyze these unconventional events promptly, and in a way that encapsulates the experiences of the people living and participating in the events.

Interviewing

Many qualitative research projects are interview-based (Britten, 1995). In health research, the qualitative interview allows for the use of probing, open-ended questions (Stuckey, 2013). These questions give participants the freedom to respond in their own words. It was important to me during these interviews that I maintained the interactive aspect of qualitative interviews while still being sensitive to the language and concepts I am eliciting from my participants (Baumbusch, 2010; Britten, 1995). As a focus of this project was the language being used during the diagnosis of endometriosis, I had to be aware of the language I exercised during the interview process. My intent with this project was not only to scratch the surface of what is going on during the interactions between women and their doctors, but I wanted to get as much detail as possible, and understand the experiences these women have had individually. Similar to the research I

have done regarding how language potentially affected the diagnostic time, it was important that the language I used during the interview process was easy for all of my participants to understand, and if it was not, that I was able to use different language so that they knew what I was asking of them.

According to Patton (1987), there are six different types of questions that can be asked in a qualitative interview. These are: behavior or experience questions, opinion or value questions, feeling questions, knowledge questions, sensory questions, and demographic questions. All categories of questions can be asked in any of the three tenses: past, present and future (Patton, 1987; Stuckey, 2013). Additionally, Patton claims that there are three stylistic choices a researcher has when deciding what sort of qualitative interview to do, these are: the informal conversational interview, the general interview guide approach, and the standardized open-ended interview. The difference between these types of interviews lies entirely in what a researcher has prepared before the interviewing process. For this project, I chose to employ the general interview guide approach, meaning I outlined a set of issues and questions that I wanted to touch on during the interview, but if other issues arose we were able to address them without feeling any constraints. The interviews for this approach are typically referred to as semi-structured interviews, the most common interview used in qualitative research (Baumbusch, 2010; Stuckey, 2013). This particular approach is advantageous to researchers because it ensures that researchers can best utilize their time with the participants in the study. The interview guide provided a framework in which I, as the

researcher, was able to develop further questions and make decisions throughout the interview about what pieces of information to further pursue.

Recruiting Participants

Often, random or probabilistic sampling is used to ensure generalizability of findings by reducing bias (Palinkas, et al., 2016). However, for this project, it was imperative that the women I interviewed had, or thought they had, endometriosis. For this, I utilized purposeful sampling. As this was a qualitative study, and I wanted to understand the experiences of these women, I was not necessarily looking for my data to be generalizable. This sampling technique has been widely used in qualitative research in order to identify and select individuals who were particularly knowledgeable or experienced about a certain interest or phenomenon. Additionally, the importance of participant availability, willingness to participate, and ability to participate are also highlighted through the use of purposeful sampling. The sampling that researchers employ in their research must be consistent with the aims and assumptions of their research project.

My recruiting methods for this project included both convenience recruiting and snowball recruiting. Convenience recruiting is a nonrandom method of recruiting in which members of the target population, who met specific criteria for this research project, were recruited based on ease of accessibility, geographic proximity, availability, and willingness to participate (Etikan, Musa, & Alkassim, 2016). Initially, I reached out to women who I had known had been diagnosed with endometriosis via text and email and asked if they would like to participate in my study. Some of these women agreed,

while there were others that I did not hear back from. Additionally, I created a flyer asking for volunteers to participate in a research project about endometriosis. After the flyer was created, I wrote up a short description of my study and shared on all of my social media platforms, including Facebook, Twitter, Snapchat, Instagram and LinkedIn. The content of these posts varied, as some of the platforms have restrictions on what you can post, such as Twitter's 240 character count, or the simple lack of space or time limit of a Snapchat post. These posts were able to reach women that I knew, but did not know had been diagnosed with endometriosis.

In the social media recruitment posts, I tried to make it clear who was eligible for the study—women who had been diagnosed with endometriosis—and included a link to a short survey. The survey included questions relating to preferred interview platforms, whether or not the participant was willing and able to participate in an interview, and if the participant has been diagnosed with endometriosis. In addition to these background questions, I required those taking the survey to include an email address. I then reached back out to the women who had indicated that they had been diagnosed with endometriosis and asked for them to fill out their availability for a verbal interview. I noted that all times were in Eastern Standard Time (EST), because I was located in that time zone and unsure of where my participants were located. Upon going through the women who had filled out the survey, I was surprised to see so many names that I knew and reminded myself that one in ten women is diagnosed with endometriosis, which is an alarming number.

Additional participants were recruited using snowball recruiting, when researchers use their primary participants as a means of finding more participants (Atkinson & Flint, 2001). Snowball recruiting, as a method, has been known to overcome problems such as sampling difficult to identify or concealed populations. As it was pertinent that my participants had been diagnosed with endometriosis, I had hoped that the participants I recruited through convenience sampling could point me in the direction of more women with endometriosis. Some of the women that participated in the study helped me get more participants by reaching out to friends they knew with endometriosis and recommending that they participate in my study. Additionally, many friends and family members shared the social media posts to their own social media which reached a broader audience of women that I did not have access to. Without other people sharing the social media recruitment posts, I do not know how successful this project would have been.

About three weeks into the recruiting process, I was still having a difficult time getting people to participate past the initial survey stage. Essentially, I could not schedule interviews or they were cancelled before the scheduled time. I decided to include women who had not been diagnosed with endometriosis, but felt as if they had it based on their experience with some of the symptoms associated with endometriosis. Once I included this group, I was able to reach ten total participants. I originally chose to exclude these women because I was worried that their experience would deviate from those who had been diagnosed and that it would make my findings unreliable. However, as I will explore in my findings and analysis, the women who had not been diagnosed with

endometriosis but believed that they had it experienced very similar things to those who had been diagnosed with the chronic pain disorder.

Collecting Data

Semi-structured interviews were conducted face-to-face, via video chat platform FaceTime and phone calls. Interview questions consisted of language that encouraged participants to talk about their experiences with their physicians during the diagnostic process of their endometriosis. In my role as the researcher, I wanted to find narratives that included the use of language during the diagnostic process. I anticipated that the language being used by both the women and their physicians in these encounters potentially contributed to the long diagnostic period of endometriosis, which sits at approximately ten years on average.

During the interviews, I utilized nearly all of Patton's (1987) categories of questioning at least once as a means of gathering the most exhaustive data possible. While there were certain questions I intended to have answered during my interviews with participants, I opted to utilize semi-structured interviewing, as I felt it was more conducive to eliciting a narrative from participants. My participants had a hand in the flow and design of the interview, as they would disclose information I was not prepared for or needed more information about, which prompted me to ask some different questions than I had prepared (Baumbush, 2010; Stuckey, 2013).

Prior to recording our interviews, I read an informed consent script to all of my participants. This script included that the study had no known risks, reassurance that participants could abstain from answering any questions, that participants could stop the

interview at any time, information about myself and my research interests, and I noted that the interview would be recorded in this verbal consent script. After reading this script I asked again if it was okay for me to record our interview and proceed with my questions. All of the women that participated agreed to be recorded.

I interviewed a total of ten women, and the average interview lasted 30 minutes and 6 seconds. I had originally anticipated that interviews would last about 45 minutes, however they were a bit shorter. I was able to use platforms such as skype and FaceTime to complete my interviews in addition to in-person and phone call interviews. Some participants were geographically out of reach for in-person interviews, so the interviews via phone calls and video calls were necessary for this project.

I recorded all of the interviews in real time on an app called Otter.ai. I had to go back and edit them, as they were not accurate. The app stored all of the interviews and required a login with a password and username in order to access them. Additionally, as a means of maintaining confidentiality, all interviews were named “Participant X” followed by a pseudonym. During the transcription process, I highlighted the passages I thought were most important and seemed to be present in many of the women’s experiences. I decided to edit some of the transcriptions for clarity, such as reducing the excessive iterations of “like” in addition to adding some words for clarity, which were put in brackets. I chose not to edit the final transcriptions too heavily when adding them to the final paper.

CHAPTER FOUR

PARTICIPANT NARRATIVES

I analyzed my interview data using an approach in which the language used and stories told by women were interpreted to see what narratives emerged. Human life is experienced and recalled as a narrative. As it is one of the oldest human activities, it only makes sense to utilize these narratives. Interview questions were designed to elicit life-experience narratives from the women that I interviewed (Greenhalgh & Hurwitz, 1999; Stuckey, 2013). These narratives did not contain information solely about the events and actions they were depicting, but also provided a map that includes the participant's general make-up. Things such as the participant's inner hurt, hope, grief, and pain were reflected upon in a narrative. Narrative research in health communication is not just about the narrative of chronic illness, such as endometriosis, but stories about lives that are reshaped by that chronic illness (Stuckey, 2013).

After reading through the interview transcripts twice, four narratives emerged from the interview data. Pain, the first narrative that emerged, was the most similar experience among my participants. For many, the pain that they experienced from their endometriosis was what led them to seek a diagnosis. The second narrative that emerged was the women's understanding and utilization of social support, which typically came from friends and family. In some instances, there was a *lack* of support that the women I interviewed believed negatively affected their own diagnostic and treatment experience. I chose to use social support as an umbrella concept, and to distinguish between those who experienced it and those who did not within that category. The third narrative that

emerged was what an endometriosis diagnosis meant for the women I interviewed. This narrative was interesting, as three of the women I interviewed had not been diagnosed with endometriosis, but believed they had the chronic pain disorder. The fourth and final narrative that emerged was the doctor-patient communication during my participants' diagnostic and treatment experiences. Although the women all had different experiences, many of them had faced very similar things during their diagnosis process.

Manifestations of Pain

The one experience that was present in every story was pain. For many women, pain was a driving force for them to go see a physician about their symptoms. Some women had experienced pain from a very young age. One participant, Robin, stood out, as she started experiencing pain at the youngest age:

So, I had always had really bad periods, I started when I was 11, and not one single time, I don't think that I ever-I mean-it's interesting, they were, they were really bad in junior high school, and then I started playing tennis, and they kind of got a little better, still very heavy, still a fair amount of pain, but I no longer had to stay home from school. And, so, I was like, okay, well I guess now that I am more active athletically, this is going to get better, and so I progressed from playing tennis to distance running.

Other women had not experienced pain until later in their lives. For some, there were events in their lives that seemed to trigger their endometriosis symptoms. Stacy, who

hasn't been diagnosed but believed she had endometriosis, started noticing pain in college after she had elected to go on birth control:

So things that kind of caught my eye were extremely painful period cramps. And those started happening, I didn't have them before I started birth control when I was 18, I only started having them after my, like, freshman year of college about when I was 19... It's like I can't walk, I can't breathe for a split second, for you know 30 seconds or whatever. I kinda just sit there and hold my breath and tense up and then wait for it to pass sort of... Also, sometimes, I don't know if this is a symptom of endometriosis or not but sometimes I'll get like, like, a period cramp when I'm not on my period and it'll just be like randomly in the middle of the day, in some random month where I'm not even near my period. And it'll just happen, and it'll be really strong, and then it'll go away and there will only ever be one, and then it'll just stop... And then, sex has always been extremely painful for me... Those are the only symptoms I can really think of. Which is why it was just something that I kind of wondered about, but I never talked to my doctor about it or anything because I wasn't sure if I had enough symptoms to like qualify.

Another woman, Lisa, described how she began experiencing pain a few years after she had given birth to her son:

It was in the year of 2012, so my son was about four or five years old, and I started to have a lot of pain with my periods, extremely heavy periods...

every month. And sometimes, you know, before and after the cycle. So they were, they were quite frequent. I would say it'd last at least a week to two weeks of on and off pain until, at one point, it was just so bad, I was in so much pain that I decided to go. I didn't have health insurance at the time that this was going on, so it was limited to how often I would go.

While all of the women that I interviewed had experienced physical pain, some also experienced emotional pain. The same woman who began experiencing pain after she gave birth to her son described how her doctor had gone ahead and had her tubes tied during an excision surgery. She mentioned how it had made her feel really sad, because she didn't realize that it was going to happen, and that she was, from that point forward, unable to have more children:

He said, what I had gone through with my pregnancy and my age, that he made a decision when he was in there, performing surgery because he had seen the endometriosis all over the organs and stuff, he decided it was okay to cut the tubes. So, he was afraid it was going to travel up. He said with your age, you know, I don't feel like you could have had children anyway, I should not anyway, because I'm 41 now and I was 39 at the time. So, I did have a really hard pregnancy. I was pretty sad to hear you know how bad it was. And what he thought was best, but there wasn't, you know, there wasn't much I could do at that point in. It was, it would be a risk, to have it, you know, having another child. So I was okay at that point, I guess, just a little sad though.

All of the women I talked to experienced pain to some degree. For many, there was that physical pain that at times could be crippling and exclude them from social events. For all, however, this physical pain was the driving force to go to the physicians about their symptoms. The pain was the origin, the beginning, of all of their stories. As with many protagonists in any story, there is something that is the spark, the beginning of their story, for the women I interviewed, it was this pain. This can be related to many hero stories, in films, books, graphic novels, and other art. All heroes have a starting point. The pain was the chronological beginning of these narrative, while it did come up frequently throughout these narratives, it was very clearly placed at the very beginning for everyone. For some, like Robin, the pain started when they were quite young, and they either assumed it was normal, or they were told it was normal by other women. In this narrative, while the pain was an unfortunate thing to experience, it was what forced these women to seek help.

I would argue that this was the part of women's experience that was the most integral to the rest of their stories. For all of these women, pain began the entire story. For some, this was going back more than a decade prior to their diagnosis. It was where everything begins, and where it all comes back in the end. For the women, it was not necessarily the beginning of a great adventure, but it was the very beginning of an important part of their lives that is now a part of their intersectional identities. In many narratives about the heroes journey, heroes come face to face with some event in the very beginning of their story that set them on some sort of course of action. This plot point, while referenced as the beginning, is revisited quite frequently throughout the heroes

journey, it is something that reminds them to keep going, to meet their end goal. For all of the women, the plot point that initiates a course of action is the physical pain, or the symptoms of endometriosis, that they experienced.

Additionally, this pain was what connected the women I interviewed to the millions that also have endometriosis. The pain connected them to their mothers, their sisters, their friends, and to me. Because this pain that is part of the experience of endometriosis is essentially part of their understanding of themselves and this chronic pain disorder, it is what helps them relate to others. This connection was able to lead to deeper relationships with women, as they were able to communicate their shared experiences without being worried about feeling invalidated, as everyone understood and could relate because of their own life experiences. For those with endometriosis the shared experience, or lack thereof, leads some to seek out social support.

Social support

For the women I talked to, a support system was very important for processing their diagnosis. Social support came in a few different forms. For some women, it was an understanding with their friends that they couldn't always do everything because of the pain they may be experiencing at any given time. Wrenna didn't necessarily always get the social support she desired and expressed her frustrations to me:

A lot of things that people don't talk about too, is like, relationships, you know? With just friends because some friends just don't get it, they're like 'oh yeah, I get cramps too' like, no. Like, it's not cramps, you know? Like I pass out, like, that's not normal.

Grace, who believes her uterine cancer diagnosis caused an endometriosis diagnosis to be bypassed, was living in Mexico teaching English when she first started experiencing pain. After the pain became unbearable, she decided to go to a physician, but wasn't confident with her knowledge of the Spanish language in a medical setting. Luckily her students, who were also her friends, were willing to help:

I was still having problems. So, one of my Mexican friends told me she had a good gynecologist and she could take me and, you know, do the translating for me... And I was in Mexico, and you know, wasn't with [my family], like, you know, my Mexican friends were just, I'm just so grateful for their support. But, it's not the same as, like, you know, like these were people I had known a few months. And I wasn't with my family, I was in another country, and I don't use the language, the logistical part of it was a nightmare... I felt so lucky to have them... I'm still grateful to this day for the people who were my students and were there helping me and, you know, I don't know what I would have done without them

For some of the women, their families played a huge role in their support, especially their mothers. Robin found out after her diagnosis that her mother had endometriosis. She told me they hadn't really talked about it until after Robin's diagnosis:

Talking to my mom for, really, the first time about her experience. And it's kind of weird now that I think back and like I never asked her about that before. But it's sort of like, she sort of, like, acted like it was no big

deal when it was happening, even though it was a really big deal for her because she didn't just have a cyst removed, she had a hysterectomy at 36. So, I don't know why we didn't talk about it before, but I think part of it was I don't think she wanted to talk about it. And to me it was like, oh yeah it was one of my mom's many surgeries, like, she had her gallbladder out she had her whatever stuff out, you know? So, it wasn't until it happened to me that I felt like, okay, now I want to know more about what happened to you.

Grace, the woman who was teaching in Mexico, returned home to the United States to have further testing and treatment done once she found out that she had uterine cancer. For her, the lack of support from her family members stood out to her and was very difficult to process. She remorsefully told me about her experience of when she returned to the US:

So I went to the local emergency room and I showed them my x-rays and I said I probably gave them the story, but nobody went with me, like the whole-I don't know what you're exactly studying-but the whole worst part of my cancer treatment was dealing with my family, who have, we have a very rocky relationship. And this was an extremely stressful time of my life. So I went to go get diagnosed, nobody went with me, I went by myself.

Wrenna experienced the loss of support after she was diagnosed with endometriosis.

After looking up some symptoms of the chronic pain disorder, she found out that it could

mean she is infertile, and her partner at the time was uncomfortable with that. Wrenna described how support can be nice, but also how devastating the loss of support can be: “And like relationships too, like, I actually was seeing somebody, and he, like, wasn’t on board with the whole infertile thing. So, it can definitely be tough.”

Looking back, I suppose I thought that, in this study, my participants would only be the receivers of social support. Whether this support was from their friends, family, or even physicians, it did not matter. However, now that I have completed my study, I am able to recognize that the women who participated were both senders and receivers of social support. These women were supplying social support for both their family and friends. One participant, Morgan, found herself in a position of support for her adoptive sister, who began exhibiting similar symptoms to her own. Morgan was quite proud to be able to help her sister:

And actually, my sister is having, like, issues right now too. Kind of like along the same lines. So, I’ve been talking to her and I’m like-because she tried a certain kind of birth control pill and it totally messed her up, and I mean, that can happen. So I was like ask your doctor for a different kind or a different method and, you know, see if that helps. And so, I’m kinda, like, helping her to push for herself too. And so I was just, like, ignoring it for however many years. And she’s adopted, so it’d be, like, interesting to see that like somebody who’s not biologically related to me also has the same thing. So, hopefully. And she has an ultrasound I guess in a couple of weeks because, once again, I told her to like push for these things... so

we'll see how that goes. But it's been, like, I guess rough, just like listening to her deal with some of the same stuff that I dealt with. But, thankfully, like, I can tell her some things that didn't really help [me] since I'm the oldest, I get to be the responsible older sister.

The person I least expected them to provide social support for was myself. However, after disclosing my familiarity with the chronic pain disorder, many women offered support. Wrenna seemed particularly interested in offering me support and even, in a way, happy that there was someone she knew that may also be experiencing what she had:

I've kind of gotten things nailed down pretty good, so if you ever, like, need some advice or anything like that, I've gotten some pretty good stuff from what has worked and what hasn't worked. So, I mean, I don't actually know, I don't know anybody else who has endo, or at least would talk about that in public. So, it's kind of nice to know that I'm not the only one.

Morgan, a woman close to my own age, encouraged me to keep looking for a doctor and to maintain hope after disclosing to her my own experience with endometriosis:

Don't get disillusioned with doctors sucking, because once you find that one that, you know, that you matter and that your experience is valid and that you're not crazy. So, I think it's definitely worth it too, like, just keep pushing and going through the motions, I guess.

Like many protagonists, the women I talked with had at least one person that was their helping hand. In any heroes journey, they are frequently faced with difficult tasks, in this instance, its getting their diagnosis, and they find allies to help them along their way. Social support in the narratives of these women was a welcomed and desired experience. For many, it was therapeutic and was what got them through the diagnostic stage of endometriosis. Many of the people that acted as social support for the women were very easy for them to obtain, as they were already an integral part of the woman's life. These include their friends and family members.

The relationship that my participants were able to cultivate through shared pain allowed for these women to engage as senders of social support for those who had not yet been diagnosed, as with Wrenna and her younger sister. It also allowed for them to engage in supporting their friends or family that had been diagnosed with endometriosis but they may not have realized it, such as Robin with her mom and Lisa with her sister. I would argue that social support is present in most health narratives, and, for these particular narratives, social support was crucial to getting through the experiences that came with a chronic pain condition, such as endometriosis.

For some, particularly Grace, social support was much harder to come by than the other women. While this was partially due to Mexico being the setting of her diagnostic experience, she recognized that because of the nature of the relationship with her family, she didn't overtly have the social support she so desired and needed all of the time. Most of the women seemed to have had very easy relationships with their mothers or other family members, and these members very easily and willingly provided support for my

participants. These were essentially the sidekicks, the people that my participants felt they could not have gone through this process without. Social support was a vital role in these women's lived experiences, whether it was because it was there and wonderful or because it was not there and awful. Social support allowed family, friends, and physicians to act as the supporting characters to the women that I interviewed; they were important to the story no matter how the support was perceived, but they were not the main protagonist or antagonist.

Patient-provider Communication

The relationship that patients have with their physicians was really important for the women that I interviewed. For many, this seemed to play an important role in whether or not they had a positive or negative experience during their diagnostic period. I particularly noticed the ways in which the women and their doctors were communicating was really important to the women I interviewed. Daphne, for example, didn't understand why her doctor kept her on hormonal birth control when it didn't seem to be helping her symptoms:

So, before the procedures, like when they were just doing the birth control. I didn't really understand, I guess, what the birth control was doing. Like, I, I understood, like, the birth control like what it does, but I didn't really understand why they were using that when it wasn't working. It wasn't being helpful.

Grace, who was used to a more holistic approach to medicine, was a bit apprehensive of her doctor that practiced western medicine. However, she realized she felt at ease with him when he used illustrations to help her understand what was going on inside her body:

It made it easier, right? I mean there's a lot of like technical terms and I don't really know what's going on, you know? I don't really know what the inside of my body looks like either, so I think that was really, you know, he can give me all these technical terms for the different layers and different organs, but actually being able to see it, that's really, really, helped me understand what was going on better.

Similar to Grace, Wrenna seemed to understand her physician more easily when she was presented with a visual that she could bring home with her. However, she also expressed that she had wished her physicians had communicated more clearly what was to be expected when it came to treatment and the chronic pain disorder in general:

He gave me some brochures and things like that, but the bulk of my knowledge really came from my own kind of research. But, again, you know, he explained the basis of 'it's your uterine lining and it grows in weird places,' yadda yadda, the whole process of it. And, you know, I did a ton of tests of course, hormones, internal ultrasounds, external ultrasounds, the works. So, other than that it was kind of just like what I found myself too, which was really helpful to understand it a little more.

For Stacy, the gender of her doctor seemed to play a role in the apprehension she had when she visited the doctor's office. I asked if she had male doctors in the past, and she

listed her pediatrician, dermatologist, and dentist. However, she said now that she's an adult, she prefers to have female physicians:

My main doctor is a woman, and I tend to prefer that because she's not a man. It was just kind of awkward, especially because he was a little bit older, and I mean, there was like a nurse in the room there too. So, like, I didn't feel in danger or anything, but it was just awkward. It was more uncomfortable than when I go to my regular gynecologist...[The specialist is] a guy, so I was a little bit more nervous around him. But, like, the second that he touched me and told me to relax, I was having trouble relaxing. And so he thought [the pain experienced during sex] was anxiety related, but even the times where I have sex where I was relaxed, because you know, drinking alcohol or whatever, I still feel pain.

Gender also played a role in how doctors approached the women's treatment options. Robin felt very frustrated when her doctor was hesitant to move forward because doing so could hurt her chances of having a baby:

One of the things he mentioned was, like, if you don't take care of it, you know, it can interfere with your ability to have children. And, you know, at that time, you know, I really didn't feel like I was someone that wanted kids, and I almost felt insulted that he assumed that that would be important to me... And I remember talking to my parents about it and I was just like, you know, it was, he just, he seemed like [he was] not going to do certain things. Like his goal going to be to preserve my

childbearing ability or preserve my health? Because I'm way more concerned about my health than my ability to have children. I was really mad about it.

Some women felt that they had a hard time getting their doctors to listen to them. Those that brought this up the most were the women who had not yet been diagnosed with endometriosis. Janet, for example, believed she had it based on the symptoms she exhibited, especially those relating to bowel movements and pain during urination, which are indicators of endometriosis. She felt very frustrated whenever she would go to the doctor and try to explain her symptoms and experience to her physicians:

It was just like ok, like, I'll listen to you for like 15 seconds, and then I'm just going to, like, order these tests for you. And, like, my company does not provide the best insurance, so pretty much I have to pay \$1,500 each year before, like, getting any kind of benefit from my insurance. So, they would be like ordering all these blood tests and I'd be going to all these doctor appointments and I'd be spending like \$900 in a month just through, like, these useless medical expenses that didn't get me anywhere. Yeah, so then, just like going through their steps, not really listening to what I had done before. Which is why I really liked this GI doctor because he listened to what I had tried already, so that was good.

While Stacy preferred her female physician, she did say it could be frustrating trying to discuss her symptoms with her doctor. Similar to Janet, she felt as if her physician wasn't listening to what she was describing:

So, I mean, sometimes I feel like she has a diagnosis in mind when I say period cramps. And she just kind of, you know, when I said, my period cramps are really painful she just took it as it's period cramps and nothing more. As for the painful sex, she, she thought that maybe it was too, too, like not being in love with the person that I was having sex with and maybe not being comfortable with them. And when I went to, when I, well one of my friends friend has like the same problem, like she has really, like it's really painful for her when she has sex, you know with her husband. And she was like 'I don't think that's the issue, I don't think its just like nervousness or not being comfortable' and she's like 'it's still painful even with him.' And so, but even when I went to that [specialist] he kinda was just like, like, Oh, you know, it's anxiety, you're nervous, because the second that I touched you, you like tensed up. I was like, Well yeah, you know I am, to some extent, afraid because it hurts. And I'm afraid of the pain. And so I don't know. Yeah, I don't know if it's, like, an anxiety related pain, like, if I just, if every month where my body is just tense down there or if there's another reason for the pain. And I just don't know. And yeah. And when I saw the [specialist] he seemed to think that it was just anxiety related.

Prior to doing the interviews that accompanied this project, I had assumed that the antagonists in the narratives that emerged would always be the physicians. This was my error, and a reflection of my own personal experience coming through. However, as

mentioned in the social support section, that was not the case. Many women described their diagnosing physicians, or the surgeons that performed excision surgery, to be what I would relate most closely to mentors or allies, not heroes. To many of my participants, these were the people who made them feel validated and as if their pain deserved to be heard. Some of these physicians provided pamphlets and drawings to help the women understand what was happening inside their bodies. This did not necessarily ring true for all of the women, some were left using Google to find out more about their conditions, the only ally aspect of their physician was they had finally told them that their pain was indeed warranted, and a couple of treatment options moving forward.

For many of the women I interviewed, the physicians who did *not* diagnose them took on a more villainous role than any other living being in their narratives. It was hard for my participants to be invalidated over and over when they knew they were experiencing this pain they were describing to their physicians. While these doctors were not necessarily harmless, as their inability to diagnose the women led to much more time spent feeling invalid, the women frequently suggested it wasn't entirely the physician's fault because of how difficult endometriosis is to diagnose. While the role they played did have features of a villain, I do not believe that they were the villains of the story. These physicians were the "gray" characters, they were not good, but they also weren't entirely bad.

I was not very surprised to see gender come up when women were discussing their physicians, as it was something that had come up in my own life as a woman and in many of my friends' lives. For Stacy, it played an important role in how comfortable she

was with her physician. She spoke of her male physician as more threatening to her than the female physician, even though it seemed like they both engaged and listened to her an equal amount, which did not seem to be very frequent. For Robin, gender was something that she felt was affecting the treatment her doctor was going to pursue. In this instance, unwelcome gender norms were forced upon Robin, and she reacted very negatively. However, she still did not describe her doctor as a villain in her story, just a frustration.

Many of the women described frustrations with their physicians, but many, particularly Morgan, were very happy with their experience and willing to recommend their physicians to other women. I would say that, in this process, recommending one's physician was a very weighted gesture, as it was one true signifier of how appreciative of their physicians these women were. People would not typically recommend something they did not value, especially when it comes to health. Again, I would not say that physicians were the heroes in these narratives, but allies, who were still quite valuable in experiences like this.

What a Diagnosis Means

For the women I interviewed, a diagnosis made a big difference for them. For some, it held significant weight in making them feel as if their concerns were validated. For others, it made them feel as if they were more connected to their mothers. Chelsea, who spent nearly eight years trying to get an answer, described to me how it felt when she finally got a diagnosis:

[I felt] validated almost. I mean, like I said, I've been doing so much internet research and so much reading at that points and my parents were

both in school studying medical things. And then, there's this whole other layer to it. I like, don't want to get too deep into my personal life because I don't want to make you feel uncomfortable. But, my birth mom-my parents-my dad and my mom separated when I was six months old, and my dad had full custody of me [my] whole life. And I've never met my birth mom, I've never met anyone on that side of the family, I don't really know anything about them. I don't really know anything about her medical history at all. My dad was like well we kind of thought she might have had, like we knew she had PCOS, but he always said that he felt like there were other things too, and the doctors had told her she might have endometriosis but she had never actually been diagnosed with it. And it's a really genetic thing, so I also felt really, kind of, I don't want to say connected in that way because I don't really feel the need to be connected to her just because I've never met her, but it was just like kind of all these puzzle pieces falling into place about my medical history on that side of the family.

For Stacy, who had not been diagnosed but believed she had endometriosis, a diagnosis meant something similar to her, but also held a lot of uncertainty:

If I knew that it was something that I couldn't fix, like it was you know a genetic thing or whatever, I would probably feel a little bit better, because, I mean it's still scary like you don't want to be diagnosed with something necessarily, but at the same time you want to know, you know? It's nice to

know what is wrong with you. So, I would probably be kinda torn both ways between relief and, like, you know, fear of what else. Like, you know, of what else comes with endometriosis.

In a similar vein, Janet did not know what could be done to help endometriosis, but she had been trying a multitude of dietary changes to see if that helped her symptoms, which were related to bowel movements and urination. She shared with me how she would feel if she was diagnosed and learned more about what she could do to help the symptoms of endometriosis:

I don't know anything about, like, what you can do to help the symptoms of endometriosis, but, I would honestly really enjoy if it wasn't dietary related, I think. And, if it was to be endometriosis, I mean, I would be happy to have an answer, that's for sure and I would be happy to be told that like, yeah I can eat ice cream and bagels

For many, the diagnosis was life-changing, because the women no longer had doubts of whether the pain was in their heads or real. Daphne, however, had quite a different experience, due to experiences when she was younger:

I wasn't too frightened, I guess, because I had, like, ovarian cancer when I was 13. So yeah, in comparison to that I was kinda like "ok, like what's another diagnosis?" ... And I think too, like, now that I'm older, and I know more about what goes into it, it's a little more frightening, but I think like when they told me it was just kind of, like it did seem as, I guess, impacted of my life as it could be, so I guess they downplayed it.

The role that a diagnosis took on seemed mostly the same for all of the women. It was this validating, almost freeing feeling, that was the denouement, if you will. A diagnosis was the final piece of many puzzles. It was the coming-together of strings, the laces tied up. Robin waited the longest of all the women, coming in at 18 years from the time that she began experiencing endometriosis symptoms at 11 years old, to the time she was finally diagnosed at 29 years old. Her diagnosis time could legally get a drink in some countries, and would be enrolled in college, a voting, legal adult! Other women were lucky enough, comparatively speaking to both Robin and the average diagnostic time, to be diagnosed within a few months of coming to their physicians. Nonetheless, all of the women that had been diagnosed had been relieved to know more about what was going on with their bodies, something the women who had not been diagnosed were still striving for.

Many of the women I interviewed worked hard to get to a diagnosis of endometriosis. I wouldn't say that endometriosis was necessarily what they were looking for, but many desired an expert opinion to validate the pain they were going through. Diagnosis was not the final chapter in the book that makes up these women's endometriosis stories. One may consider diagnosis as the last chapter in one book of many that encompasses each of these women's endometriosis stories. I say this because diagnosis helped many women open doors, doors that led them to both western treatment options and more holistic treatment options like yoga and supplements. The diagnosis helped these women figure out, at the very least, what they may be able to do to relieve the pain that they had been living with since the beginning of their journey.

Throughout my analysis I have wondered who the antagonist was, every story about a hero has one. There are many famous villains that we are familiar with throughout popular culture. As I mentioned previously, I thought the person that would play the antagonists role was the physicians that misdiagnosed the women, it seemed most obvious when doing my literature review and looking back on my own experience. However, after having combed through my interviews and read the pieces of this narrative, again, I believe that the antagonist in these stories is endometriosis. I believe that it was so difficult to realize this because it is not a living breathing being, I cannot assign a face to endometriosis, it does not breathe, or bleed, it just is. Given the pain, both emotionally and physically, that this invisible condition inflicts without any regard, I can confidently say that endometriosis is the invisible villain that is present in all of the narratives I heard.

CHAPTER FIVE

DISCUSSION

Implications

The stories that these women shared with me weave an intricate story of the intersections of endometriosis, patient-provider relationships, dialogism, and social support. All four of these pieces must be understood in order to fully understand the experiences that women are having during the diagnostic process of endometriosis. Research on endometriosis indicates the difficulty of diagnosing the chronic pain disorder (Hsu, et al., 2010; Krebs & Schoenbauer, 2019), and the women who I interviewed recognized that it was difficult. Many, even after waiting for years and going through misdiagnoses, would still empathize with their physicians.

The most notable and frequent narrative throughout my interviews were those about pain. The women I talked to all experienced pain to some extent, and, for many, it was what led them to get diagnosed. The pain matches that which was described in many studies on endometriosis (Ballard, et al., 2006; Hsu, et al., 2010; Krebs & Schoenbauer, 2019; Rao, et al., 2019). However, when hearing about the pain from the women I interviewed, their words lent a much more real understanding of the pain that other women go through, compared to reading about it in studies. As was my intention, understanding the narratives of my participants allowed for this more personal understanding of the pain rather than a clinical understanding of the pain that is experienced.

The patient-provider relationship was very important to the participants in this study, which supported the research that on this subject (Hellin, 2002; Kaba & Sooriakumaran, 2007; Steinhart, 2002). Patients and physicians must cultivate a good relationship in which the patient feels comfortable disclosing information with their physician. This relationship can be disrupted for those with endometriosis when they are led to feel invalidated by their physician, thus leading them to disclose less. However, the responsibility of this relationship does not lie entirely in the physician's lap; patients must be willing to work with them, even in difficult times. Both of these actors, as Bakhtin (2010) would describe them, must be willing to compromise throughout the dialogue for the other, facilitating a dialogue that potentially benefits both.

Regarding dialogism, which Bakhtin (2010) described as a constantly evolving three-way drama, the diagnostic process is simply the first part of this drama. The actors in this first part of the drama are the patients as senders and receivers, their support as senders and receivers, their physicians as senders and receivers, their pain as subject, and their diagnosis as subject. My project only sought to understand the diagnostic period. However, there is still the process of treatment, and, because there is no cure, women will typically return to their physicians after an excision surgery for more excision surgery as the cysts tend to grow back after some time. This led me to suggest that there were still many actors and subjects that my participants have faced and must face in their journey with endometriosis.

The relationship my participants had with their physicians was not the only example of dialogism throughout this experience. Because I chose to utilize narrative

analyses methods, dialogue was of the utmost importance. During this process, I was an actor, my participants were an actor, and their story was an actor. The way we interacted and communicated with each other gave meaning to their experiences and stories. While these women told me their stories, each part of their stories informed the others, each answer to a question informed me and led to my next question. While I did have prepared questions, a strength of using the semi-structured approach was that it was not necessary for my participants to answer all prepared questions, it was only necessary that they shared their stories in a way that was logical for both themselves and for me. The experiences these women had were what was most important to me and understanding how each piece informed another and myself was the most important part of this project.

During this project, I asked myself several times what the difference between a thematic and narrative analyses were, they seem practically the same. However, after having thought about it for a while it is clear to me that while they are quite similar, they are still different. Both methods find themes that are prevalent in the data, however, how these themes are analyzed is different. I found that when doing a narrative analysis, I was able to place these themes in a certain time. For example, pain and diagnosis were major themes, but they were temporally located at the beginning and end of every story I heard. While pain specifically was also located throughout most of them, it was the driving factor for many women to seek out help. Additionally, those in the ally role had a role that was very similar throughout, it wasn't just some overarching theme, these people—doctors, friends, family, coworkers—were playing, or failing to play, very specific roles in the stories of diagnosis of this chronic pain condition.

Gender was not discussed outright frequently. However, when it was, the women felt very strongly about the roles that were being forced upon them or the communication occurring between the two genders. Two women stand out very specifically to me, Stacy and Robin. Stacy was uncomfortable with the gender of a specialist she was recommended to see, and Robin was uncomfortable with her physician's concern about her fertility over her health. Robin's specifically can be traced back to the historical approach to women in medicine, that women were seen as child bearers first and foremost. Robin was not comfortable with being confined to this incredibly traditional gender expectation placed upon her by her physician. Women's bodies have been policed for centuries, and it should not be surprising to researchers that this is still occurring, as it was the precedent in which women's health was founded.

A lot of uncertainty surrounds endometriosis, whether it is the symptoms that come with it, the severity of those symptoms, or the treatment options that women have when they are finally diagnosed. When people are faced with uncertainty, we tend to turn towards others as a form of social support. Many women that participated in this study chose to use the women in their lives as forms of social support. Some women also found themselves in positions of social support. The relationship and decision-making that led women to choose to help others that may have endometriosis likely stems from the invalidity these women may have experienced when trying to get a diagnosis themselves. As Clarke, et al. (2014) and Nguyen, et al. (2012) suggested, many people with chronic pain conditions feel as if their peers and physicians challenge the experiences that they are living. I suggest that this is why the women participating in my study offered support

to myself and other women in their lives—because they did not want us to feel this sense of invalidity.

Limitations

Endometriosis is severely understudied in an academic setting, so this project was able to offer some insight into what it is like for women who seek out an endometriosis diagnosis. While this research may offer helpful insight into getting chronic pain disorders diagnosed, some limitations still existed throughout the project. The largest limitation was diversity amongst participants. All participants self-identified as Caucasian women, many being in their mid-twenties. This means that, while the data is useful, it cannot be generalized to speak for the experiences of all women seeking an endometriosis study. Women of color have been conceptualized by physicians as noncompliant, lacking motivation and having difficulty communicating (Burgess, et al., 2019). This conceptualization of women of color in the healthcare industry likely affects their experiences when trying to get chronic pain disorders, such as endometriosis, diagnosed.

In addition to a lack of ethnic diversity, I did not ask my participants what socioeconomic background they came from or if they had insurance. I did not think to ask this until I talked to my last participant, Lisa. Lisa told me that she had a hard time getting diagnosed with endometriosis because she did not have insurance, so she could not afford to go as frequently to get her symptoms checked as she may have liked. I think that understanding my participants more holistically, including resources available to them, could have changed my approach and offered a more well-rounded account of the

experiences they have had. However, because of the time constraints on this project, I was unable to get to know them more wholly. If I were to do a longer study about this, that is one thing I would aim to do.

Future Directions for Research

First, this study should be recreated to include a more diverse sample to get a more encompassing understanding of the experiences women have with their physicians during the diagnostic process of endometriosis. Because my sample was only Caucasian women, I cannot speak to the experiences that women of other ethnicities have had when trying to get endometriosis diagnosed. As far as researchers know, endometriosis affects Caucasian and Asian women at higher rates than any other ethnic group (Rao, 2019).

However, Johnson and Quinlan (2019) suggest that this is not necessarily true:

Until 1966 endometriosis was thought to be a “white woman’s” disease, and as late as 1997 gynecologists diagnosed African American women with pelvic inflammatory disease instead of endometriosis; many were sterilized as a result of this misdiagnosis. (p. 50-51)

Like much of women’s health, I worry that the history of this disease shaped the way in which doctors and researchers approach the chronic pain disorder. The notion that, only 23 years ago, African-Americans were being misdiagnosed and effectively sterilized, leads me to believe that this is absolutely a direction future research owes to the women that have the chronic pain condition.

Additionally, I believe that researchers should do a study comparing the experiences of women who either have endometriosis or think they have endometriosis and have access to their healthcare systems and those who do not have access to their healthcare systems. While a study like this may not be applicable around the world, I do think that this study would give an insight into how those without insurance and access to healthcare systems are able to diagnose, treat, and live with their chronic pain disorders. Chronic pain disorders do not discriminate. They do not pick only to affect the people who have access to their healthcare systems, chronic pain can affect anyone, and this is why I think this is a direction in which research regarding endometriosis, or any chronic pain disorder, should progress. Research is important for giving a voice to the voiceless, and I think those who do not have access to their healthcare systems have been silenced and their voices should be heard.

Finally, a study like this could be expanded to include primary-care physicians and OB/GYNs. I recognize that endometriosis is a difficult disorder to diagnose, due to the large range in symptoms and the high discrepancy in symptom severity (Hsu, et al., 2010). I believe that understanding the experience of physicians throughout the diagnostic phase of endometriosis could help give a better understanding of why the diagnostic time is an average of 10 years. By understanding this, medical institutions could perhaps create measures to help physicians more fully understand and feel more prepared to diagnose endometriosis. This body of research could also help women and researchers more fully understand why it can take so long to be diagnosed with endometriosis.

In general, there needs to be more research done about endometriosis. More specifically, about the women who are living with endometriosis and the impacts it has on their lives. While there are some academic studies regarding endometriosis, many take a more medical approach to the disorder (Huntington & Gilmour, 2005). There are not nearly as many as there should be about the women who live with the disorder for a condition that affects ten percent of everyone with a uterus.

CHAPTER SIX

CONCLUSION

After I completed interviewing all ten of my participants, I reflected upon my own experiences with, what I believe to be, endometriosis. I felt I was able to connect with many of these women, especially regarding the pain we have experienced and the interactions with physicians. I mentioned in the introduction to this project that I have avoided going to the doctors for a while now because I have been anxious about being invalidated, as I have been before. It is an exhausting experience, and yet the majority of my participants persevered through it. Hearing these women's experiences, I recognized that they are the heroes of their own stories. They were able to get their diagnosis, with the help of their physicians, family, and friends. However, I do not find myself assuming the hero role, in my own story. Right now, it feels as if these women are my heroes.

Many of these women acted as a social support outlet for me after our interviews when I disclosed my interest in the topic. These women showed incredible strength and courage when standing up for themselves. For me, they've given me the courage to continue seeking out help and to figure out what is going on inside my body. As many women mentioned, this is not normal, excruciating pain should not be something that I accept. I do plan to see someone, and to keep fighting to be heard, however this does not mean that I am not afraid of doing so, I am terrified. I think that this fear is what makes me feel that I am not the hero of my story. I haven't done the thing yet, and I have been afraid to for years. Hopefully, one day, I am able to feel as if I am. For now though, I am

happy to have had the privilege to speak to these courageous women, who have profoundly impacted me and given myself courage.

Endometriosis is a chronic pain condition that can take a significant toll on the millions of women it affects. Women who believe they have endometriosis must face an unrelenting amount of pain in most circumstances to be taken seriously by their family, friends, and physicians. For the women I interviewed, these people also took on roles of support during the diagnostic process, when the women were finally diagnosed, and after diagnosis. The relationships that the women I interviewed built between their family, friends, and physicians were vital to them coping with the chronic pain condition. Not everyone involved necessarily played the parts that the women had hoped to assign them, such as Grace's family making her experience worse than if they had not been involved. However, I stand by saying that these people—the friends, families, and physicians—were sidekicks and allies in the fight for a diagnosis. The real heroes were the women themselves. These women were heroes not only for themselves, but for their sisters, their mothers, and even me. Following this study, I believe it is imperative to expand the research on endometriosis and the women that have it.

APPENDICES

APPENDIX A

Interview Script

To begin: Debriefing and informed consent

Interview Questions

- Can you describe for me what it was like when you first started experiencing symptoms of endometriosis?
- How did you describe these symptoms to your healthcare provider?
- What kind of language did your healthcare provider use to respond to the disclosure of your symptoms?
- Can you describe how your healthcare provider's response made you feel?
- What did your doctor say to you that was helpful during your diagnosis process?
- What did your doctor say to you that was not helpful during your diagnosis process?

***To end interview:** Thank you for taking part in my research. If during the transcription process I have questions about your answers, or what meaning you meant to convey with them, I would like to follow up with you. If you are comfortable with me following up with any questions I may have, would you please give me your name, phone number, and email? Thank you.*

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