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Selina Hays

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“IT’S JUST A BAD PERIOD” AND OTHER WAYS OF DISMISSING  
WOMEN’S PAIN: AN ETHNOGRAPHIC LOOK INTO THE EXPERIENCE OF  
ENDOMETRIOSIS

by

SELINA HAYS

A thesis submitted in partial fulfillment of the requirements  
for the Honors in the Major Program in Anthropology  
in the College of Sciences  
and in the Burnett Honors College  
at the University of Central Florida  
Orlando, Florida

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Co-Chair: Dr. Nesselte Falu

## **Abstract**

This thesis uses online ethnographic methods to analyze the impact of patriarchal values on the illness experiences of women with endometriosis. Current literature suggests that negative impact on patients with endometriosis with regard to cultural discourse surrounding menstruation and chronic illness. Utilizing a combination of critical discourse analysis and constructivist grounded theory, the results of this research demonstrate that patients engage in a form of performance that is reactive to normalization and dismissal of pain by doctors and wider social support due in part to cultural stigmas of menstruation and chronic pain, as well as the inherent power imbalance in the doctor-patient relationship. This performative role as a patient also creates a reclamation of power by participants in the form of strong medical familiarity and casual use of medical terminology. The intent to benefit future research are discussed with the limitations of this study.

## **Acknowledgements**

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## Contents

ACKNOWLEDGEMENTS	III
INTRODUCTION	1
CHAPTER 2: LITERATURE REVIEW	4
Endometriosis	4
Menstruation Taboos and Endometriosis	4
Impact of Endometriosis on Relationships and Sexual Fulfilment	7
Disruptions to Life and Productivity	9
Impact on Fertility	10
Theoretical Considerations	12
CHAPTER 3: METHODS	16
Recruitment	17
Interviews	17
CHAPTER 4: RESULTS	19
Pain as “Normal”	19
Medical Knowledge as Power	21
Role of Patient as Performance	25
CHAPTER 5: DISCUSSION AND CONCLUSION	30
Limitations to Research	31
Implications for Future Research	31

EXPLANATION OF RESEARCH	33
INTERVIEW QUESTION GUIDE:	35
IRB APPROVAL LETTER	36
REFERENCES	38

## Introduction

The United States Office on Women's Health estimates 11 percent of American women aged 15 to 44 years old is affected by the disease endometriosis. Endometriosis is a gynecological condition where the tissues of the uterine lining (endometrium) grow outside of the uterus, attaching to other places in the body. The most immediate areas affected are the reproductive organs: the fallopian tubes, uterus, and ovaries. Endometriosis can also commonly affect the vagina, cervix, and rectum. Although rare, endometrial tissue has also been detected in the stomach, lungs, brain, and skin. This tissue responds to the hormones released during menstruation, swelling and bleeding inside of the body. The swelling associated with endometrial tissue often blocks the fallopian tubes, fuses ovaries to the inside of the body and uterus, and causes scar tissue and adhesions on the bladder, intestines, and bowel (*Office on Women's Health, 2019*). Endometriosis swelling causes significant debilitating pain, akin to early labor pains for some. Despite the severe impact endometriosis has on the quality of life for patients who live with it, the diagnostic delay for the disease is ten years on average, with symptoms often dismissed or attributed to other conditions. The devastating effects on quality of life and significant delay in diagnosis make endometriosis a unique illness that begs the question, how do patriarchal cultural values impact the illness experiences of those with endometriosis?

Oxford dictionary defines patriarchy as: a system of society or government in which men hold the power and women are largely excluded from it. With this context, this study seeks to understand how women with endometriosis must navigate a system like the medical field while being subject to wider cultural stigma, especially the association of endometriosis with menstruation. The reviewed literature will touch upon this relationship between menstrual stigma and endometriosis. To fully understand the correlation, I will utilize Arthur Kleinman's

framework of meanings to illness, as well as key definitions for ‘illness’ and ‘disease’. From this, attention will be paid to feminist theory. I will examine Judith Butler’s theory of gender performance, as well as feminist standpoint theory. This combination of theory guided the analysis of data.

Given the rise in technological accessibility in recent history, the way the internet has become incorporated into daily life creates an interesting area of study. One specific influence the internet has had on our culture that merits anthropological inquiry is in how medicine has been impacted. One of the top health and well-being information websites, WebMD, has been available to internet users since it was founded as Healthscape in 1996. With medical information growing readily available to anyone with an internet connection for around twenty-three years, this ease of accessibility has undoubtedly influenced medicine as a science. While worth further study, this research does not focus on issues of accuracy of the information available. This research uses the internet as a site of research – specifically, I will be using the Reddit community thread r/endo as a means of gathering participants to interview as well as observing and analyzing posts users make to the main thread. Reddit is a United States-based social news aggregation and discussion forum. As of December 2019, the site had 430 million active users monthly, with 26.4 million from the United States alone: of US internet users on Reddit, 22 percent are between 18-29 years old, 14 percent are 30-49, and 7 percent are 50 or older; of those that identified a gender, 15 percent are male and 8 percent are female (Clement, 2019). It is my intention to demonstrate not only the importance of Internet based research, but also the validity.

An important consideration I must make is my own experiences with chronic pain. Having lifelong chronic shoulder pain allows for a sense of relativity to this research that is



unique. I am also seeking to bridge a gap in the way anthropology explores the reality in which living with chronic pain in a world conditioned to minimize and diminish the experience takes a psychological toll on those who are diagnosed with it. While anthropologists have examined the experiences of those with chronic pain, with respect to chronic pelvic pain, as well as the way in which a patriarchal society minimizes women's experience, I hope to provide a different perspective. As a person with chronic pain and one who identifies as a woman, I feel this ability to relate in one sense can aid in my own self-reflexivity in the face of asking my participants to be self-reflexive in the isolating experience of the conjunction of these two identities that endometriosis presents. I feel this uniquely qualifies me to an area of research where other anthropologists may lack an understanding or way of accessing. Through my own training in ethnography, I place confidence in my ability to evaluate my participant's expressions of their experiences in a way that adds an addition to the knowledge currently held about endometriosis. I aim to contextualize it within the literature that currently exists on the topic. The findings of this study will aim to produce reliable results that will also aid future researchers in endeavors to explore this topic.

## Chapter 2: Literature Review

### *Endometriosis*

Endometriosis is a topic that anthropologists have examined for the way it has uniquely debilitated those with its extreme symptoms (Bloski & Pierson, 2008). The quality of life for women is greatly diminished whilst living with the disease. The conjunction of its effects on the vital aspects of daily life, such as general well-being, work ability, relationships, and mental health have been given in-depth review by biomedical scientists (Nnoaham et al., 2011; Gupta et al., 2018; Ballard, Lowton, & Wright, 2006). Scholarship sourced for this review of relevant literature uses an interdisciplinary approach; I will examine literature from biomedicine, sociology, anthropology, and women's and gender theorists.

### *Menstruation Taboos and Endometriosis*

Firstly, we will examine diagnosis and how it is impacted by wider menstrual taboos. An estimated 176 million women are affected worldwide, which in turn only reflects approximately 10% of all and 30%–50% of symptomatic premenopausal women (Nnoaham et al., 2011). An average of 11.7 years occurs between first reporting of symptoms and official diagnosis for women with endometriosis in the United States (Ballard, Lowton, & Wright, 2006; Ballweg, 2004). The idea of the “etiquette of menstruation” (Seear, 2009) plays an important part in examining the unusual impact cultural influence has specifically on endometriosis and the statistically long delay in diagnosis. The United States has upheld a societal notion that a woman's period is to be concealed. Most commonly, focus has been given to its ties to the tabooed nature of a woman's menstrual cycle and the minimization of women's suffering (McMillan & Jenkins, 2016). A common theme explored in feminist scholarship is the way patriarchal society shames and demonizes the experience of menstruation (Payne et al., 2016;

Fingerson 2006, p. 17-19). “Menstrual taboos” come in many forms: they tell women they are unclean, or menstruation is a private experience and should remain hidden (Bobel, 2010; Fingerson, 2006; McMillan & Jenkins, 2016). Societal discourses tell women that their feminine hygiene products should make no noise when opened, sell them harmful scented versions, demonstrate them with blue-dyed water in commercials rather than be presented with the sight of blood on something to use in the aid of collecting the products of menstruation. We are presented with the idea that a woman on her period is expected to act a certain way, that the cultural dictations of what she should do to conceal it are to be upheld (McMillan & Jenkins, 2016). This cultural idea of forcing privacy upon the process of menstruating has been shown to be debilitating to the female adolescent experience. Research by Schooler, Ward, Merriwether, and Caruthers (2005) has demonstrated the correlation between menstrual shame and negative body self-image and less body comfort in undergraduate college women aged 17 – 23. Their study shows the relationship that an openness toward menstruation has on sexual assertiveness and sex positivity; the women in this study who responded with a more positive attitude toward menstruation reported more comfort with their bodies overall, whereas the women who reported feelings of shame and discomfort with menstruation also reported lack of sexual experience or risk-taking when sexually active. Openness toward menstruation has with regards to promoting a heightened understanding for young women about their bodies. In the decades since the height of Second Wave feminism, and a renewed push during the current Fourth Wave, women are encouraged to be more open with their experiences with menstruation (Bobel, 2010). This does not, however, exclude the examples of the patriarchy affecting the way in which young women view themselves. It is uncommon for girls in early reproductive age to be surgically diagnosed with endometriosis, no matter how “textbook” their symptoms may seem (Martins et al., 2014).

Studies into adolescent boys and girls have shown that the tendency to brush aside indications of excessive pelvic pain, nausea, and fatigue occurs within the peer groups of those who may be living with endometriosis (Gupta et al., 2018). It can be argued that menstrual shame and stigma is an essential reason why this occurs. As Kleinman (1988) argues, when symptoms of an illness are culturally marked, they mark the person too. Here, we can begin to see how endometriosis symptoms are culturally tied with the stigmas surrounding menstruation and it marks women with this stigmatization from puberty. In turn, it also colors the way they experience the rest of their life.

Overwhelmingly throughout the reviewed literature, research has indicated that women with endometriosis seem to present a voyeuristic and disassociated relationship with their own pain. A study done by Stella Bullo, which focuses on the experience of endometriosis by examining statements made by those diagnosed with the disease using discourse analysis, shows that a common recurrence among women interviewed is using disempowered language when speaking about their experiences. Respondents use phrases indicating repulsion, lack of femininity, brokenness, and a sense of being abnormal as well as language that indicates that their disease is a battle against their doctor's and social group's disbelief and lack of understanding (Bullo, 2018). As examined previously, negative associations of menstruation correlate with negative body image, lowered sexual self-efficacy, and self-consciousness with regards to the body and sexual experiences (Schooler et al., 2005). When those affected by endometriosis continuously use terms like "broken" or "damaged goods" in their statements (Bullo, 2018), we can begin to see how a society that values male health and needs over that of women impacts those who are burdened by a reproductive disease of this severity. Women living with endometriosis may believe symptoms are part of a "normal" menstruation, especially if

there is a family history of “difficult periods,” or fears of appearing unable to cope with “female problems” (Bloski & Pierson, 2008). When combined with the prevalent narratives of women citing fear of social stigma and the dismissal of symptoms by family and medical practitioners, one can infer the psychological toll this would take on the average woman with endometriosis. Overall, the weight of the evidence points to higher rates of depression, anxiety, and emotional distress than control groups and the general population (Culley et al., 2013).

### *Impact of Endometriosis on Relationships and Sexual Fulfilment*

As stated, illness can take significant meaning from the sick person’s social world. This leads us into examining the ways endometriosis impacts areas of daily life, like relationships, work, and family planning. By understanding how many areas of life being chronically ill with endometriosis impacts, we can begin to see how the sick person’s social and personal world influences the meanings of their illness experience (Kleinman, 1988). A huge source of stress endometriosis adds to daily life is its impact on maintaining an intimate relationship and female sexuality. Those who are afflicted with endometriosis report experiencing painful sexual intercourse, issues with infertility, and the lack of understanding from their partners as a significant point of stress on their lives (Culley et al., 2017). Those that report instances of painful sexual intercourse also report pressure to still engage with their partners sexually from their partners, by their peer groups, and from general cultural expectations surrounding the female experience (Culley et al., 2017; Fingerson, 2006). Those with endometriosis report that when engaging in sex, they experience responses to painful sex including starting but then stopping intercourse; changing positions; enduring intercourse because of a desire for pregnancy and enduring intercourse because of a reluctance to allow endometriosis to affect yet another aspect of life or because of a desire for closeness with a partner (Culley et al., 2017; Fingerson,

2006). Young women exhibiting the symptoms of endometriosis through painful sexual intercourse cite the inability to speak to their partners about it, as well as the pressures to uphold gender norms and women feeling generally unattractive and unfeminine as reasons not to disclose discomfort to partners (Gupta et al., 2018; Culley et al., 2017). For those with more understanding partners, it still presents a stressor on intimate relationships, as shown below regarding men's experiences in having a partner with endometriosis. US culture places increased pressure on the importance of sex within a relationship; so, for those who may be able to be open with partners about issues with painful sex, the repeated lack of sexual contact may still present an issue between partners long term (Culley et al., 2017; Fingerson, 2006).

This stress on romantic relationships can be due to the men's perceptions of their partner's experience of their disease. Reports of tension between men seeking to acknowledge dissatisfaction with the impact of endometriosis on sex and intimacy while also seeking to avoid appearing to 'blame' their female partner or being perceived as selfish or unreasonable are common, as well as partners reporting that they seemingly accepted in a way of "just learning to live with it", despite not reporting any resolutions to their feelings of dissatisfaction (Culley et al., 2017). When the aspect of infertility is added, yet more insight into the psychological and emotional toll is revealed. Below I will provide a more in depth look into the impact of infertility on women with endometriosis, but it is important to understand how in addition to issues with sex in relationships, the prospect of infertility is a significant stress on within an intimate relationship as well. While most men studied report that the emotional impact of infertility was greater for their partner, some men still report that their partner's endometriosis affecting or disrupting their plans for future children is a source of disappointment, stress, and/or trauma (Culley et al., 2017; Fingerson, 2006; Gupta et al., 2018).

### *Disruptions to Life and Productivity*

The more “discreet” aspects of endometriosis are even more severely underreported. Cultural stigmas regarding talk of bowel movements whether they’re “normal”, or as is the case for many women with endometriosis, “abnormal, painful, or embarrassing” (Gupta et al., 2018) prevent those with endometriosis from often seeking relief or speaking about these symptoms at all. Participants to Gupta’s study resolutely responded with nervousness and embarrassment at the suggestion of speaking even with their friends about the gastrointestinal issues associated with endometriosis. Despite the hypothetical nature presented in this study, it does represent the greater societal way with which we react to female bodily functions, especially when those functions are considered out of the norm.

The ability to work is of great importance to the average American woman in 2019. With endometriosis, just being absent from work does not describe the full spectrum of disease-related work productivity loss. In a country without government funded healthcare, like the United States, one can infer the correlation between the delay in diagnosis and work absenteeism, with lowered productivity when present. To gather the meaningful estimates, both presenteeism (defined as reduced productivity while at work) and absenteeism (the time lost from work) must be considered (Nnoaham et al., 2011). This should consider time from work lost to monthly endometriosis symptoms, a reduction in productivity at work while symptomatic, and potential time lost to surgery or other medical procedure necessary for the management of endometriosis. Menstrual pain, incapacitating pain, abdominal pain and depression predict poor performance at work, with several papers suggesting that women's endometriosis symptoms - particularly these pain symptoms – have an impact on productivity at work, with between 23 and 66% reporting limitations in their ability to perform work-related activities (Culley et al., 2013). As mentioned

above, diagnostic delays exist between the time when a woman may first seek to alleviate endometriotic symptoms and official surgical diagnosis. This can allude to the financial toll endometriosis can present upon those diagnosed. Informing employers of their diagnosis of endometriosis and of its symptoms causes tensions for women, as while it is felt to be a private condition, women also need support in employment, with women finding the greatest difficulty in informing male employers for fears of repercussions, impact on potential financial earnings, and a general fear of the shame and trivialization from men in regards to past experiences of being disbelieved (Culley et al., 2013).

### *Impact on Fertility*

An understanding of the impact that the high rates of infertility women with endometriosis face must be considered. The lack of study into endometriosis-related infertility is a serious gap in the narrative of the disease anthropologically. Since infertility is a common result of diagnosing and treating endometriosis, looking into studies that focus on it are a key in understanding the greater implications of the disease, even if the relevant studies do not reference the disease specifically. As previously explained, women with this disease live with a disproportional level of recurrent pelvic pain that can lead to a diagnosis of endometriosis when they seek relief. For women who may possibly live with these symptoms but do not report it or feel the need to seek medical attention, a diagnosis comes when they discover they may be infertile due to endometriosis. Asymptomatic women with endometriosis commonly may not know they have the disease until they are unsuccessful when trying to become pregnant. Scholarly reports of infertility show the ways in which social support can aide those who live with infertility and a lack of support from family and partners can result in a significant source of stress (Martins et al., 2014). One method of permanently treating endometriosis is surgically



removing part or all the uterus, known as a hysterectomy (Ballweg, 2004; Warren et al., 2018). With an estimated 590,000 hysterectomies performed annually, over 100,000 of them are done as treatment for endometriosis (Kyama et al., 2007). This would permanently render a woman infertile. This adds a deeper level to living with endometriosis, as it presents a future without children that many women may not expect before diagnosis (Culley et al., 2017). Women with endometriosis, especially those that are officially surgically diagnosed, are given the bleak reality that they are statistically predisposed to the inability to bear children, which is a potentially huge source of trauma (Martins et al., 2014).

### *Gaps in the Literature*

It is also important to note the apparent lack of research into non-cisgender patients or couples. I have found that most of the current research focuses on heterosexual couples and cisgender women. The nonbinary or transgender experience with endometriosis does not seem to have many, if any, peer-reviewed research as of right now. There is also a dearth of research on the experience of endometriosis on communities of color, as most research appears to focus on predominantly white populations. This is not to say that endometriosis does not affect people of color; a simple Google search provides articles and support communities for women of color. One study points out that the inconsistent numbers for women of color seeking medical attention for endometriosis symptoms can be attributed to the high rates of these women seeking professional help by private doctors, as opposed to public health services (Kyama et al., 2007). Another important note to make here is that the risks for differing types of endometriosis, such as cervical or uterine, are more predominant in African-American women but less diagnosed than in White women, but overall endometriosis affects women in general at the same rates with minor margins based on race (Kyama et al., 2007; Keshavarz et al., 2002).

This research seeks to shed light on the unique experience that the isolation of an invisible disease and chronic pain that is marred by the deeply misogynistic cultural pressures we place on issues involving menstruation. I aim to build onto the theories discussed by other scholars, like those of Arthur Kleinman and Judith Butler, in a way that can be applied to analysis of the stigma of both chronic pain and menstruation. It is the unique way in which women with endometriosis can only report on the composite of these that presents a distinct relevance to the area of anthropological study. With this understanding, this research seeks to expand our understanding of the illness experience of endometriosis using the patient's own self-reflexivity. Using curated posts in addition to interviews wherein the participants have a heightened ability to edit and frame their own narrative, it is my intention to use theory to analyze how endometriosis as an illness is experienced. The unique way this research uses the internet as a site of study lends a level of anonymity for participants that other endometriosis research lacks.

### *Theoretical Considerations*

This research takes several theoretical frameworks into consideration and draws heavily from feminist-medical anthropology as an overall approach.

In order to fully answer the research question at hand, we must examine how women with endometriosis are impacted in several aspects of lives by their illness, as well as how menstrual stigmas implanted within society affect the meaning of their illness experience. I use Arthur Kleinman's (1988) definition of illness: "how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability". To this, Kleinman refers to 'disease' as "what the practitioner creates in the recasting of illness in terms of theories of disorder" (Kleinman 1988). It is vital to understand the distinctions between terms

like ‘illness’ and ‘disease.’ They present very different ways in which to analyze the meaning of a woman’s understanding of her own sickness. Kleinman outlines an important theoretical framework of meanings to illness, two of which I will use to analyze the literature on this relationship. First, Kleinman states that illness takes significant meaning from vital aspects of the sick person’s social and personal world (Kleinman, 1988, p.10). Second, illnesses and their symptoms are culturally marked, and the meanings of these symptoms mark the sick person in turn (p.18). By using ‘illness’ in a very humanistic sense, I will convey how the experience of living with endometriosis cannot be understood without also understanding how social stigma of menstruation by patriarchal cultural practices impacts that experience.

Attention must be paid to feminist theory, with consideration for Judith Butler’s theory of gender performativity (1990). The theory refers to the wider effects that gender as a performative act has on us as individuals. The basis for Butler’s original theory traces back to language philosopher J.L. Austin’s 1962 speech act theory. Austin posits that sentences are either “constative”, that they say something, or “performative”, that they do something. Butler’s theory then applies this to gender:

“Such acts, gestures, enactments, generally construed, are performative in the sense that the essence or identity that they otherwise purport to express are fabrications manufactured and sustained through corporeal signs and other discursive means. That the gendered body is performative suggests that it has no ontological status apart from the various acts which constitute its reality. (Butler, 1999, p.185)

As explained by Laura Ahearn:

“In other words, gender is not something we have in an unchanging, essentialistic [sic] way but rather something we do repeatedly, continuously... throughout our lives. In

short, Butler takes Austin's insight that to say is to do and transforms it into a claim that to say or do is to be. Rather than being expressive of a pre-existing, stable identity, then, gender is performative, Butler argues, because people's social and linguistic practices "effectively constitute the identity they are said to express or reveal" (Butler 1999[1990]:p. 192)." Ahearn 2016, p. 185).

From here, Elise Kramer's application of Butler's theory to feminist linguistic anthropology is important in contextualizing how gender performativity as a concept will be understood in this research; discourses about gender don't just constrain behavior to certain extant categories, but actively *create* the categories in the first place (Kramer 2016, 67). Kramer argues that linguistic and gender performativity are reactive and enabled by cultural discourse, but they also function because they inherently assume the creation of the discourses in the first place. Therefore, performativity in this context is important to the context of this research. We can understand performative language here to not only be that saying something is doing something, but that language use can also indicate a performance itself has also taken place. Ahearn points out that Butler herself understands this aspect of her theory:

"Moreover, my theory sometimes waffles between understanding performativity as linguistic and casting it as theatrical. I have come to think that the two are invariably related, chiasmically[sic] so, and that a reconsideration of the speech act as an instance of power invariably draws attention to both its theatrical and linguistic dimensions . . . [T]he speech act is at once performed (and thus theatrical, presented to an audience, subject to interpretation), and linguistic, inducing a set of effects through its implied relation to linguistic conventions (1999[1990]:xxvi – xxvii)." (Ahearn 2016, p. 187)

Butler's theory applies the use of linguistic practices to the embodiment of gender and individual identity formation. When we apply this to the identity as an endometriosis patient, we can begin with the understanding that cultural discourses of womanhood already impact the disease experience. This discourse involves stigmas of menstruation, womanhood, chronic illness, and in some instances, stigmas within medicine itself. All of this impacts the specific experience of being chronically ill with endometriosis in a way that impacts other areas of life for these women. It is my intention to demonstrate how this performative gender role has adapted to medicine in a unique way for women with endometriosis. Through this research, we can see how damaging wider cultural discourses create and reinforce ideas that severely effect the ways women are treated within medicine, and it is my intention to demonstrate how women as patients with endometriosis are impacted specifically.

Attention must also be paid to Feminist Standpoint theory. Standpoint feminism posits three claims: 1. Knowledge is socially situated. 2. Marginalized groups are socially situated in ways that make it more possible for them to be aware of things and ask questions than it is for the non-marginalized. 3. Research, particularly that focused on power relations, should begin with the lives of the marginalized (Bowell, 2020). Utilizing a framework of theory that centers the knowledge gained from researching women is a critical component of this thesis. I suggest that the specific knowledge produced by women with endometriosis is key in understanding the subjugation of women's bodies when they live with an invisible illness. Feminist standpoint theory as a guiding context then helps to situate how women with endometriosis navigate the power relations inherent in a medical setting. We can understand here how women with endometriosis experience their bodies as a site of subjugation as the results of this study will demonstrate.

### **Chapter 3: Methods**

This research is a “net-nography” (Horst & Miller, 2012). My site for the research of this thesis was the social media site Reddit, with specific focus on the forum r/endo, which is dedicated to the discussion of endometriosis. A combination of constructivist grounded theory and critical discourse analysis was used to analyze data gathered from May through December 2019. The two main approaches this research followed were primarily feminist linguistic anthropology and digital ethnographic methodology. As this research includes two methods of data collection, saved posts were compiled in a single document, without any identifiable data, for further analysis. All interviews were conducted over Reddit’s private messaging feature and were later saved in a single document without any user information; all participants were given a random name and no information beyond age, nationality, and email addresses were collected. None of the participant’s Reddit usernames were recorded. This was done to ensure the age requirements were met for participation as well as to provide a study information letter. This research received exempt status from the UCF Institutional Review Board for the protection of human subjects (STUDY00000245).

By having the Reddit app on my personal phone, using an account set up specifically for this research, and my own familiarity with Reddit, it was my intention to utilize a digital ethnographic approach. In order to recreate an “in world” situation, saving posts that were relevant to the research in real time was done to replicate a situation in which non-participant observation could be achieved. Posts on the thread include things like “rants” about general illness experience, humorous “meme” images, and questions about symptoms and medications. This was done by analyzing for themes utilizing initial coding and constructivist grounded theory. These saved posts were later analyzed using critical discourse analysis, as with any posts

made before the time research began that were saved for their relevance to the research. Simultaneously, analysis of the interviews was being done using the same methods.

Twelve individual semi-structured interviews were conducted during the duration of May through August 2019 with r/endo users who responded to an initial post I made asking for participants on May 13, 2019. From June through December 2019, I analyzed past r/endo posts and concurrently saved posts as they appeared for analysis. Using an online platform as the research site allowed for wider sampling for participants: of the twelve, six participants live in the United States, two live in the United Kingdom, and one participant each live in Australia, Canada, Guatemala, and New Zealand respectively. Ages range from 19-34 years old.

### *Recruitment*

In order to gather participants for this study, I made two posts with a brief explanation of this research and asked people subscribed to the forum to respond to either me privately or comment on the post itself. The posts were made months apart. Upon receiving comments on the posts, I would message each person privately and explain the research further and ask if they would be interested in being interviewed. Between the two posts, a total of eighteen r/endo users expressed interest in being interviewed; over time, twelve actual interviews were completed. This presents a limitation to online ethnography, as I lost contact with the six potential participants because they simply just stopped responding or replied after the completion of research.

### *Interviews*

After the first few questions regarding participation, I began all interviews by asking every participant the same three questions: *Please tell me about your initial diagnosis? Had you heard*

*of endometriosis before being diagnosed? If you had heard of endometriosis before official diagnosis, what led you to believe you have endometriosis?* The goal was to get an initial conversation started about their illness experience. I then tailored each question I asked to them personally. I wanted each interview to be more like a conversation to break down some of the barriers I could have faced given my field site. Essentially, the interview process felt like Instant Messaging or a chatroom. This also allowed for my participants to control the way their illness experience was presented; because of the delay in time between messages, participants could edit and choose what they wanted to say. It allows for a way of expressing themselves that benefits the results of this research in the form of self-reflexivity. Allowing participants to be reflexive adds authenticity to their responses in a way that compliments the observational nature of saving posts from the main thread.

### *Analysis*

Using line-by-line coding as put forth by Charmaz in *Constructing Grounded Theory*, the twelve individual interviews were analyzed for themes. These themes were used to narrow down relevant posts to save when looking through the thread's post history, as well as during the time of this research. The results of this analysis are expanded upon below.



## Chapter 4: Results

Key to understanding the point of view of this analysis is the idea of performativity as an endometriosis patient. Analysis of the individual interviews and the saved thread posts has yielded two main themes we must explore first before understanding how this performative patient role is created; 1) we must examine the ways that normalizing pain from a young age impacts the illness experiences of women with endometriosis; 2) attention must be given to the use of medical knowledge – meaning here terminology, familiarity with tests and medications, and things of this nature - and their relationship to the patient’s body creates power for women with endometriosis.

### *Pain as “Normal”*

All the participants to the research expressed what they felt as a sort of normalization of their pain in a wide social context. This idea of reproductive pain being normal for women was a prevailing concept that has impacted this research. If the participants themselves did not expressly state that they were told it was normal to be in pain or that the severity itself was, they implied that they believed this to be true on some level. For instance, Rose and Maggie stated that they began their first menstrual cycles at elementary school age, starting with what they described as heavy bleeding and intense physical pain. This normalization of their intense and near constant physical pain was enacted upon many of the respondents from sometimes as early as nine years old:

Maggie: When you are 10 and complaining of severe pain, they assume first that you are simply freaked out by periods and blood. So there were several instances of being counseled by an obgyn to what periods are. The pain was minimized, but my family was aware that this was not correct.

Rose: I started my period at age 11 and had horrible cramps and bleeding. I was told this was normal and was put on birth control in 5th grade and have been on it since. It still didn't inhibit [many] of the issues and I was diagnosed with anxiety and IBS and was told that painful heavy periods were normal for some women.

Further, one can begin to see the iterations of distrust and fear toward doctors they expressed; this dismissal of their severe pain as normal led to the participants expressing expectations and experiences with feeling like their illness experience lacked value. This was shown in recollections of experiences with doctors, like April: *"After 4 visits, I literally cried in her office and begged for surgery. I never had an appointment with her again."* Lily also expressed frustration at this lack of value her complaints of pain had from her doctors:

The gyns I went to dismissed my pain every time I went to them. The only reason one finally agreed to the surgery was because I was in the ER every month for a couple of months in a row. Prior to that they would say I'm too young for it to be endo, that it was in my head, that I needed to relax and not stress, and a myriad of other bullshit answers.

Lily further expresses that she felt "disheartened" by this dismissal of her pain as worthy of treatment. This frustration at the expense of devaluing a patient's wellbeing are a product of this normalization of pain during menstruation.

Normalizing pain, often through completely dismissing it, over the course of years impacts the power imbalance women already feel in the role as patient. This inherent normalization manifests itself in women expressing fear at being labeled a "drug seeker", stress and anxiety at booking and attending doctor's appointments, and in turn creates unique mechanisms of defense that are attempts at rectifying this power imbalance.

### *Medical Knowledge as Power*

By normalizing their pain in such a way from an early age, it has created a very specific way of experiencing illness for these women. This normalization of pain experienced by the individual participants was mirrored in posts by r/endo users; it begins to become apparent that as a reaction to this constant dismissal of their pain, the women who live with endometriosis use medical knowledge as a form of power and self-advocacy. By being well-versed in medical terminology, the users expressed a level of self-satisfaction at being successful in their own self-advocacy with their doctors. The women who live with endometriosis must experience the ritual of seeing a doctor in a very specific way; those with chronic pain tend to be well-versed in what to expect from a visit with a new doctor that differs from the average person. Those with endometriosis are used to having people in positions of power within medicine - whether they are emergency room staff, general practitioners, or specialists – women with endometriosis overwhelmingly expect to be met with disbelief or even hostility. This is clearly the result of having had these previous experiences from as early as nine years old, and it makes sense that they would expect to be treated in such a manner after years. Often, intimate medical knowledge about their condition and themselves is a defense mechanism. One of the biggest obstacles that the r/endo users face is whether a doctor will take them seriously or dismiss them. By arming themselves with lists of prepared questions, specific tests to ask for, and treatments they would like to try, the r/endo users often seemingly over-prepare for an average doctor's visit as a result of mistreatment in the past.

To this, a trend of using medical terms and an intimate understanding of the effects of medicine are thrown casually around spaces like r/endo. One striking example comes from an interaction on a post involving a “joke”:

*Cramps got me like [image with text that says:] “My cramps act like I won’t take 30 Ibuprofen and take us both out.”*

user 1: I've definitely ended up in the hospital from taking too much ibuprofen because the pain just wouldn't stop. Endo shouldn't play chicken with me. I'm stupid and desperate enough to nearly kill myself to put an end to the pain.

user 2: just wondering, what does too much ibuprofen look like? how much were you taking if you don't mind me asking? i know it's kind of like a running joke around here how much we all take it LOL but this is the first i'm hearing of someone actually going to the hospital for it!

user 1: I consistently was taking anywhere from 10-16 ibuprofen a day (and some days even more than that). It was...not wise. Cue me spending Christmas 2017 in the ER in the worst pain I've ever experienced in my entire life. My kidneys rebelled and the pain was nearly indescribable. Like someone was literally holding a burning torch up to them and was slowly roasting them alive. The pain was easily an 11/10 and was so extreme that my body was panicking and forced me to vomit uncontrollably every 5 minutes...for 6 hours straight. And honestly the vomiting was more like I was having a seizure than vomiting. My whole body would tense up and convulse and the doctor honestly actually thought I *was* having seizures it was so bad. Eventually after they'd tried just about every anti-nausea and pain med they could with no success they just dosed me with morphine. Thank god for whoever invented that stuff.

So yeah. Don't overdose on ibuprofen. -100/10 do not recommend (though morphine, 15/10 *do* recommend).

This same post began with a joke image about abusing over-the-counter pain medications, includes instances of different users comparing doses and what works for them as well as people from differing countries comparing the advice their respective healthcare providers gave them regarding the same medication.

Additional instance of this use of general familiarity with medicine as a reclamation of power come from instances of the patient either being in the medical field or having an immediate person in their social circle who is. Two participants to this study had mothers who worked in some form of medicine, one being a women's health therapist and the other a nurse, and one patient had the advice from a friend's physician's assistant mother. These participants were all those who expressed less hostility and dismissal from their doctors, and all were diagnosed earlier in life. These three participants all also expressed more familiarity with their condition as well. Seen here with Ellie, having an advocate so young impacted the experience of living with endometriosis in a positive way.

Ellie: .....Because this started when I was 12, my mom was the one who found my doctors and took me to appointments. I don't know how long she spent searching for my doctor at the time, because to me she just said "We're going to the doctor". I've never had issues with doctors not taking my pain seriously or dismissing it as "just period pain".

This was replicated in posts made to the main thread as well:

User 1: "Doc & colleague in one case (more recent years), I want to make that disclaimer. It does allow me to probably push back a little more. Though I 100% believe we should feel empowered to advocate for ourselves, regardless of job. I

also know WAY easier said than done. I've written a few times in the sub how this year mentally crushed me. The lack of understanding seems also with many women (not in medicine) too. My mother in law was just asking my husband why I was still in pain after lap/many excisions. He was like "they cut a bunch out of her!". I told him its why I usually don't bother even talking about it.

User 2: ".....can you explain what you mean by "push-back"?"

User 1: By "push back" there is a concept in medicine called the "VIP patient", which are not just people like Beyoncé, but other doctors, family/friends of doctors, etc. At this point in my career I'm often treated as a peer (P advanced degrees already from somewhere else & all that's left for current PhD program is finishing dissertation). As a somewhat "peer" I do think if I disagree it is more likely that MDs will be like "fine" which is what is seen with the VIP patient phenomenon. This also is a horrible way about things as they've found the outcomes of this treatment is WORSE because doctors deviate from what they would do procedurally or question their instincts, so it's honestly not something you want. The part that is helpful is in direction and decision making if I completely disagree. Doesn't always work, and that breaking point was a resident that didn't know me during a severe episode before my lap that treated me like I was drug seeking. Though my response when she came back with a script of a med I had tried before that did not work for severe pain of "you can mark me down now as non-compliant and keep this" did eventually get another doctor in the room.

I get why my husband told his mother I was having surgery, he doesn't talk much. And the reason I heard his response was HIS annoyance at her lack of understanding so I'm thankful for that. But it is a super isolating disease. I'm in public health & endo is used in in teaching in SO many examples, but without feeling it I still think it's hard to understand. It's not common enough where people hear about it daily nor can you see it like a broken bone.

By being more medically aware, via social support or their own individual education, impacts the distribution of power in the doctor-patient relationship for certain women with endometriosis.

An aspect of this use of medical knowledge as a source of power can be seen when the r/endo users enact a performative patient role. When speaking to me in the interviews, the power shifted to an educational one, when most of the participants immediately used medical terminology to speak to me clinically at first. When speaking to each other, the users used medical terms as a source of legitimacy, as well to guide others who were starting off without a formal diagnosis. Often, in this context the users would essentially teach newer r/endo users the terminology to use when going into visits with new doctors, providing them with a vocabulary that would help provide them with agency.

### *Role of Patient as Performance*

An immediately apparent result of the way endometriosis is impacted by wider cultural values is in the level of performativity enacted by an endometriosis patient. Here, we are understanding performativity as a product of the methodology; the nature of the research asks participants to recall specific events in life, events I argue where they were enacting a performance as Butler defines it, one that is an addition to gender performance. This aspect of

gender performativity, one expressed by endometriosis patients, is a reaction to the power imbalance within doctor-patient relationships and social stigmas of chronic pain and menstruation. The doctor-patient relationship between a woman with endometriosis and their doctor is the site of a specific loyalty that is the direct effect of the long-term chronic reproductive pain felt by these women in conjunction with not being taken seriously in previous doctor-patient interactions and the normalization of their specific pain. The average woman with endometriosis cycles through a progression of disbelief that leaves them in intense pain that some expressed as being akin to childbirth. Upon their successful use of their medical knowledge and navigation, these patients express loyalty to a doctor that they find adequately relieves their pain. Because of the average diagnostic delay being years, combined with the “shopping” for doctors they often face, these women develop a performance as a patient that is based on their past experiences with doctors. This performative aspect to their role as patient impacts their wider illness experience as well.

The consequence of being told that your pain is “normal” is why this performative patient role exists for women with endometriosis. These women have created a way of behaving as a patient that can be applied to people with chronic illnesses in general; the ability to be a stoic patient is a talent that certain patients inherently have and others try to mirror as a result of the impressions all people with chronic illness, specifically those with chronic pain, try and inhabit. These women do not want to be labeled as nuisances in their doctor’s eyes, so they behave in a way that gets them the results - here being a pain-free quality of life – that they want. Even though many of these women “shop” for doctors, the power in this specific relationship still resides within the medical practitioner’s hands. This is a nuanced relationship that most of these women – whether “officially” diagnosed or not – navigate. This navigation is just another level



of stress added to their illness experience. The role as a patient that these women enact is a result of years of crafting a persona from other doctors, their staff, and general social stigma toward reproductive pain.

This performative aspect of being a chronic pain patient was present in the interviews prominently. My initial question revolving my participants individual diagnosis brought this performance out in them; all the interviews initially began with a clinical tone that mirrored a doctor's visit. Delving into their individual illness experience helped to break down the defensive quality of this performance, in addition to the informality of the interview process I created, but the need to slip into it was always present in my interviews because of the nature of our conversations. When asked about their diagnosis and general disease experience, the participants would use medical terminology and list the procedures they had had done in an almost rehearsed tone that was apparent through text. When questioned further about aspects of being ill that were specific to their experience, most would begin using shorthand or more casual ways of typing. This shift in tone was noticeable in the posts I observed, as well. An example can be seen here from a comment on a post from a user asking for help with a list of pre-operation questions for their doctor:

C1: If you are going to an expert excision specialist if endo is located (which I 100% whole heartedly recommend) make sure the GYN understands to not touch anything. It will only cause adhesions, which will cause more pain generators for you in the future. If the GYN has not had atleast [sic] 10,000 hours in the OR with endometriosis specifically, don't let them touch your endo. If they bounce back and forth between delivering babies and endometriosis speciality [sic] surgeries, do not let them touch your endo. Ablations are not an appropriate treatment option for this disease anymore. (You probably already know that). If they leave endometriosis behind and believe they

can treat it with hormone treatment drugs, this is a bad sign too. Best of luck sweetheart. You are doing good things for yourself. 🍷🍷🍷

Mod: The adhesions are caused by having laparoscopy, whether anything is done or not. They can be caused by opening the sealed abdomen by incisions and exposing the inside of the body to the air etc.

I am not sure if there is any evidence to suggest that non-expert treatment (eg, ablation or partial excision) is more likely to cause adhesions than simply a diagnostic laparoscopy where nothing is removed or treated. If you do know of any research suggesting this, please let me know.

Ideally nobody should have surgery for known or suspected endo unless it is performed by a specialist surgeon with training in advanced minimal access gynaecological surgery and specific experience in endometriosis. Unfortunately ideal access to medical treatment isn't possible for many people, so sometimes other options can be better than nothing.

OP: Yeah, the only way she agreed to do a diagnostic is because I am also going in for a tubal ligation. It's not ideal at all, but I am grateful that someone is going to take a look and hopefully give me some info. I also trust my doc a lot even though she isn't a specialist, so that helps. Thanks for the advice and info!

Here, the switch between formally speaking about medical information and informal conversation are shown. This specific example shows the levels of formal versus informal this performance as a patient creates, too. When speaking to me, participants edited themselves and spoke to like I did not know what endometriosis was at times. When speaking with each other in comments on posts, users have an unspoken understanding with each other that changes the way they enact their reactionary patient performance. Most often, they would take on a position of power and guidance for others who expressed a need for help.

This performativity was expressed differently in interviews, as there was the inherent lack of association as an endometriosis patient between myself and my participants. Instead, expressions of this can be inferred from the ways they described their experiences and the reflexivity that was created through the method of data collection. When speaking of their condition, not only did participants express normalization of their symptoms from outside forces, they also enacted a form of this when speaking to me. Words like ‘typical’ and ‘normal’ were used to explain aspects of their symptoms to me, participants would over explain tests and terminology, or they would explain things they presumed I did not know. All of this showcases how the wider implications of their disease experience have impacted the way they interact with medicine; because most of the respondents had gone through years of dismissal, or explaining things to people, or explaining themselves to new doctors, it creates an association of their disease with these aspects that impacts the way they interact with the wider world. By calling back to Butler’s theory of gender performativity, an aspect of this performance is that it is often unintentional on the part of the individual because this performance has been created and twisted by societal expectations.

This performative role as a patient is not unique to women with endometriosis; the results of this study are limited to its scope of those living with endometriosis. There are wider implications of chronic pain, to the extent that the disease itself and the discourses surrounding it could create each their own unique illness experience.

## Chapter 5: Discussion and Conclusion

Understanding the relationship between gender and performance is vital to understanding this nuanced relationship for women with endometriosis. I argue that patriarchal cultural values not only create this normalization of pain that acts in a way that prevents patients from receiving adequate treatment, or more often, creates the ten year diagnostic delay; reactionary to this, patients with endometriosis attempt to rectify the doctor-patient power imbalance, one that is overwhelmingly disproportionate for women with endometriosis, by using medical knowledge and wider familiarity as a source of power. Finally, the wider social implications of living with endometriosis impacts the illness experiences of its patients by creating a patient performativity, one that effects the ways that these patients interact with not only their medical selves but also their overall social surroundings. I argue that the patriarchal values that are subconsciously upheld within society force young women with endometriosis to begin enacting a new way of viewing themselves medically that is directly related to wider social stigma on menstruation and women's pain. This in turn impacts how these patients enact and interact with gender; it would be impossible to separate the implications of gender on endometriosis illness experiences. A disease like endometriosis suggests an inherent gendering that its symptoms and those diagnosed cannot escape. It is a disease that impacts female sex reproductive organs, and because of this the wider stigmas associated with women are applied to the illness experience. These stigmas and patterns influence how women experience being ill. This is demonstrated clearly in the reactive performative role women take on as a patient. This can be understood as the situated knowledge women with endometriosis create as the marginalized group within feminist standpoint theory. This knowledge, which in this sense is the performative role enacted by women with endometriosis, is born out of the situation created by the patriarchal value system in place.

Endometriosis is the site of a very specific subjugation of women's bodies, one that capitalizes from the invisible nature of the disease. This turns the performative role I found to exist into a sort of symbolic mask, one that is a defense mechanism. This mask is used to deflect the expected dismissal and hostility, as it also serves to enact a sort of credibility in the eyes of the doctor. This situation exists because of stigma and shame associated with deeply ingrained values within society, values that cater to male bodies more than women's.

### *Limitations to Research*

The limitations of this research lie in the limit of its scope; future research would benefit from wider comparison of Internet support groups for endometriosis, such as Facebook or disease specific sites like Nancy's Nook. A prominent limitation to this research is its focus on those living with endometriosis. It is likely that other communities for chronic pain or chronic illness also demonstrate some level to of the results found here.

### *Implications for Future Research*

It is my intention that the results of this study be used to the benefit of expanding research further. The nature of this research benefits greatly from gender studies and further investigation can be made into gender theory within medicine. An area that would benefit greatly is in the relationship between doctors and patients, especially those with other chronic conditions. An immediate theme of this research was in how doctors and their endometriosis patients interact with each other, as told from the patient's point of view. In turn, the result of a performative patient role and how this may apply to other diseases is an area of study would impact the wider illness experience greatly, and not just for endometriosis patients. Above all, it is my intention for this study to be a basis for further interdisciplinary research.

**Appendix:**  
**Explanation of Research**



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CENTRAL FLORIDA

## **EXPLANATION OF RESEARCH**

You are being invited to take part in a research study. Whether you take part is up to you.

This study will use a series of interviews in order to provide an anthropological understanding of chronic pain as it relates to the gendered power dynamics and experiences of endometriosis.

You will be interviewed about your experience with the disease endometriosis and how it impacts your life. Participants located in or close to Orlando will be interviewed at a mutually agreed upon private location. All other interviews will be conducted by phone or video call (Skype or FaceTime).

The expected duration of your participation should total no longer than one hour, depending on availability.

You will be audio or video recorded during this study. If you do not want to be recorded, you will not be able to be in the study. Discuss this with the researcher or a research team member. If you are recorded, the recording will be kept in a locked, safe place. The recording will be erased or destroyed after it is finished being transcribed and all information such as your name and contact information will be replaced with a pseudonym.

Your name and face or voice will be collected during the interview process, but all identifiable information will be deleted upon transcription.

All interview transcripts will be deidentified and will be stored on a password protected laptop for a minimum of 5 years (per UCF policy).

You must be 18-64 years of age or older and have been diagnosed with endometriosis to take part in this research study.

**Study contact for questions about the study or to report a problem:** If you have questions, concerns, or complaints Selina Hays, Undergraduate Student, Department of Anthropology at [REDACTED] or by email at Selina.hays@knights.ucf.edu or Dr. Beatriz Reyes-Foster, Principal Investigator, Department of Anthropology at (407) 823-2206 or by email at Beatriz.Reyes-Foster@ucf.edu.

**IRB contact about your rights in this study or to report a complaint:** If you have questions about your rights as a research participant, or have concerns about the conduct of this study, please contact Institutional Review Board (IRB), University of Central Florida, Office of Research, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901, or email irb@ucf.edu.

**Appendix:**  
**Interview Guide**



## **Interview Question Guide:**

1. Tell me about yourself and your initial diagnosis.
2. What words would you use to describe your pain?
3. Had you heard of endometriosis before being diagnosed?
4. What led you to believe you have endometriosis?
5. What do you look for in a “good” doctor?
6. Tell me about your relationship with your doctor.
7. How would you describe your [loved ones] relationship to your disease?
8. In what ways, if any, do you feel the need to explain your pain/justify symptoms?
9. Do you find that it is easier to explain endometriosis to women vs men?
10. Did you have to make any changes to how you live because of endometriosis?
11. Does having endometriosis impact the partners you choose? If so, in what ways?
12. Does having endometriosis effect how you see yourself? If yes, in what ways?
13. Do you feel as though you must make an effort to avoid letting endometriosis impact certain areas of your life?
14. Can you explain how your endometriosis has affected your plans for your future?

**Appendix:**

**IRB Approval Letter**



UNIVERSITY OF CENTRAL FLORIDA

**Institutional Review Board**

FWA00000351  
IRB00001138  
Office of Research  
12201 Research Parkway  
Orlando, FL 32826-3246

EXEMPTION DETERMINATION

November 26, 2019

Dear Beatriz Reyes-Foster:

On 11/26/2019, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Modification / Update, Exempt Category
Title:	"It's Just a Bad Period" and Other Ways of Dismissing Women's Pain: An Ethnographic Look into the Experience of Endometriosis
Investigator:	Beatriz Reyes-Foster
IRB ID:	MOD00000474
Funding:	None
Grant ID:	None

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or [irb@ucf.edu](mailto:irb@ucf.edu). Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Kamille Chaparro  
Designated Reviewer

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