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Endometriosis: The Psychosocial and Emotional Lived Experience of College-Aged Women

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and Renée Crown University Honors
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Honors Thesis in Anthropology

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Abstract

Endometriosis is a condition thought to affect as many as one in ten women. It is most commonly associated with infertility, intense abdominal pain, which may affect a woman's ability to work and maintain social relationships; and pain during sex, which may prevent or challenge her in maintaining a sexually active relationship. On top of the ways in which women's daily lives are affected by this condition, the women who experience endometriosis are also subject to having their symptoms dismissed by their doctors as either "catastrophizing" or psychosomatic

This two-part project explores the real-life experiences of women who suffer from endometriosis. In the first phase, this is achieved through in-depth research into the literature which has already been produced. Though a fair amount of work has been produced on the lived experience about women of childbearing age, there still remains a large gap in the literature for the exploration of the lived experiences of adolescent women who have only recently received an endometriosis diagnosis. The second phase involves the use of semi-structured interviewing to explore the lived experiences of college-aged women who have received an endometriosis diagnosis. Using the ideas of liminality and stigma, the psychosocial suffering that is produced as a result of this chronic illness can be clearly seen to complicate the physical pain the woman already experiences.

Executive Summary

This project aims to examine how endometriosis, a chronic illness affecting women and closely associated with pelvic pain and infertility, is experienced by female students at Syracuse University. Endometriosis is a condition which occurs when the tissue which lines the inside of the uterus begins to also grow outside of it. This tissue, called endometrium, is responsible for the swelling and bleeding associated with female menstruation. When this tissue grows outside of where it is meant to, it continues to bleed as a result of the woman's menstrual cycle but has no means to exit the body. This causes pelvic pain as well as the production of scar tissue inside the woman's body.

This paper is the result of the first part of a two-phase research plan. The first task associated with this phase was to gain approval from Syracuse University's Institutional Review Board, which ensures that any study that involves the active participation of humans will not bring harm to those same people. Next, a semi-structured interview was compiled, consisting of twenty-two open-ended questions. These questions focused on the woman's symptoms, when they arose, how they affect different parts of her life, and how she deals with these symptoms. They also cover how the woman feels about her diagnosis, and how she believes her support system understands her experience.

This phase also depended heavily upon an in-depth literature review, which explored much of the current literature surrounding the experiences of women with endometriosis. Throughout the literature, four key themes became clear. First, most women expressed frustration with her clinicians for minimizing, if not totally dismissing, the pain she was experiencing. Secondly, many women waited years before they finally received a diagnosis, a phenomenon known as the diagnosis gap. Next, many women mentioned that they felt the

need to ignore the pain she experiences so that she may continue to be a productive member of society. Finally, experiencing pain during intercourse, another common symptom of this condition, was frequently cited as, at the very least, complicating relationships, if not preventing them all together.

On top of the physical and often painful symptoms of endometriosis rests the emotional pain produced by how society views this chronic illness. Using the concepts of liminality, invisibility, and stigma, I argue that society devalues the women suffering from endometriosis as a result for their failure to obey certain societal norms. Liminality refers to someone or something existing between two normally expected categories. This state is often considered polluting, as this mixing of categories is confusing to the ways in which people understand the world and are heavily avoided (Douglas 2003). Additionally, liminality allows people to move outside the bounds of normally expected behavior, though this may cause her to be excluded from certain spaces (Turner 1969).

Invisibility also negatively impacts women with endometriosis. Because there is no readily visible sign of the condition, the disease itself is invisible. This allows others to ignore the experiences of suffering that these women must endure. This often causes both doctors and family alike to dismiss their suffering as a whole.

Finally, both the invisibility and liminality of the condition cause women with endometriosis to be stigmatized. Stigma, defined as “a mark of disgrace that represents a socially devalued status” (Ohan 2018), similarly increases the psychosocial suffering that the woman experiences. Because her pain has no visible cause and she cannot return to health, friends and physicians alike may blame the woman for making up her symptoms and refuse to provide her with support, which negatively affects her health outcome. A chronic illness such as this is also socially disrupting, in that it may prevent the woman from being a productive member of society. In the United States, productivity is highly valued. As a result of the pain associated with endometriosis, a woman may not be able to fulfill her typical social role as a productive member of society, which disrupts her sense of self. This negatively impacts the woman.

This project is significant because it examines how young women cope with a potentially debilitating illness. College is a crucial time for women with endometriosis, as it often coincides with when a woman first receives a proper diagnosis. It is important to consider this time as it provides insight into how women come to terms with and understand her illness. Currently, there is no literature which examines this age demographic and how it relates to their endometriosis diagnosis. This research aims to start to fill the gap in the literature regarding the experience of endometriosis, and more broadly illness, in young women receiving a diagnosis for the first time. On a larger scale, this paper also provides readers with a means to understand both the physical and psychological suffering of others.

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Preface

I grew up in a Catholic Italian household. In my family, we rarely speak about reproductive health. Conversations about sex are entirely off limits. Growing up, these always felt like forbidden topics. For a long time, I did not consider even lightly discussing them because I thought that one day I would all of a sudden understand the female body and what it means to be a woman in society. After years of curiosity I decided to dive into YouTube to understand the life experiences of different women.

This background blossomed in college. For the first time I had the opportunity to not only take classes on feminism, but also gender, sexuality, and reproductive health. During this time, I also came across Arthur Kleinman's book, *Illness Narratives*. As an anthropology student who wanted nothing more than to go to medical school, this book truly spoke to me. To take a full history of the patient, how she understands her illness, and how her illness impacts her life and her relationships should always be the goal of every physician, so that she may have a full understanding about who her patient is and how she interacts with the world. This not only makes the patient feel heard, but also establishes a stronger relationship between physician and patient. It also leads to better care of the patient.

Although I do not have endometriosis, I was introduced to the topic through Facebook. As I am interested in issues of women's health I wanted to explore the lived experience of people with endometriosis. So many women suffer in silence because they do not understand what they are experiencing is not "normal". My inspiration for this topic also came from a place of education, as I believe that every woman should have at the very least a basic understanding of her body and how it works. Through my research, I hope to bring more visibility to this condition that affects as much as ten percent of the female population!

Though I am incredibly passionate about this research, I did run into a few obstacles. They will be discussed in greater detail in the first chapter of this paper, but it is important to note that, because I struggled with multiple aspects of this research, I was forced to reorganize the way in which I conducted my research and how it will be presented. As a result, my research will be completed in two phases. The first phase focused on receiving approval for my project by Syracuse University's Institutional Review Board, formulating my interview guide, and conducting an in-depth literature review regarding the lived experiences of endometriosis. My second phase will involve conducting many more interviews surrounding the lived experiences of endometriosis in college-aged women. Once finished, I plan to submit my analysis to be published.

Though I seem to be lagging behind, I have never once given up hope that I will finish this research. I adore my topic, and it would take a true act of divinity to make me stop pursuing this research after coming so far. I plan to continue recruiting participants through the summer and begin the in-depth analysis of my results in the fall. Although this is only the first phase, it is a good basis which I will lean heavily into as I begin the analysis segment of my research.

Acknowledgements

From the bottom of my heart, I would like to thank Dr. Lane, my capstone advisor, for her tireless support. No matter if I needed help with the structure of my research, direction towards theory I could bury myself in, or just a kick in the pants, you were always there and willing to do what it takes. This project hit a lot of speed bumps, but every time a problem would come up, you always had a solution to get me back on track. I truly could never have done it without you. I would also like to thank Dr. Hromadzic, my advisor within anthropology, for always cheering me on. Your words of encouragement did more than you could ever possibly know. A big thank you to my roommates over the past two years, for allowing me to use them as a sounding board when I got stuck and for reminding me to take care of myself even during my busiest times. Finally, I would like to thank my parents for raising me to believe I could do anything I set my mind to and to stick with it even when the going gets rough. I would not be here without all of your support, and I am eternally grateful.

Advice to Future Honors Students

First, I would like to mention that completing your capstone is not nearly as terrifying as it originally seems. It will definitely result in late nights to beat deadlines and countless hours scouring databases to find the information you need to make sense of it all, but don't let that scare you away from beginning it. This project is the most rewarding thing I have worked on throughout my undergraduate career, and I feel so lucky that I had the opportunity, as an undergraduate, to design and conduct my own original research.

That being said, don't bite off more than you can chew. I ran into multiple issues while conducting this research, ranging from getting approval from the University in the first place to finding enough participants to be involved in my study. This resulted in my dividing my research into two parts, only the first of which is presented here. With the knowledge I have now, and likely more time, I would have been able to turn in an entirely completed project. This has not deterred me, however, as I intend to continue with my second phase of research whose end product will be published. Make sure you have the time and the sample you need to start your research, otherwise you may be left scrambling as I was.

Finally, do not forget to lean on your friends and family and take care of yourself. Producing my capstone has been more rigorous than any other assignment I have ever taken on. It has required more focus and more drive than I even knew I had. It seems attractive to dedicate every ounce of your being to completing your research, but make sure to take breaks. This will prevent burnout as well as improve the quality of work that you produce. Being able to walk away from it for a little while will certainly have positive impacts on your work as well as your mental health!

Honestly, at the end of the day, your capstone should be something that excites you. If you don’t love the work that you are doing, you picked the wrong project. It should be fun. It should be something you care about. Honors has given you the space to discover yourself as an academic and work on something that is meaningful to you. Enjoy it!

Chapter 1

Barriers to Research

Difficulty Acquiring Approval

From the inception of this project, there have been many obstacles to overcome, the first of which being receiving timely approval from Syracuse University's Institutional Review Board (IRB). Because this research involved the participation of human subjects, it was necessary to go through the university's IRB to ensure that the rights of these participants remain protected. As an undergraduate student conducting original research for the first time, I was unaware of all of the necessary steps required to receive this approval. Initially, I had intended to include the recruitment of sorority women in my research plan, and thus in my IRB application as well. My original plan was to ask each sorority on Syracuse University's campus if I could attend one of their weekly meetings. Once there, I would give a short presentation educating the audience on both endometriosis and my project. After I finished this presentation, I would announce that I was looking for women to participate in my study and if anyone wished to participate, that I would leave my contact information with whomever was running the meeting.

I wished to pursue this mode of recruitment, as I believed it would establish more rapport with the women I wished to interview. It is significantly easier to interact with a person one has already communicated with face to face. I believed that establishing a relationship early on would produce a maximum amount of participation for my study. What I did not realize was that to actively recruit an organization such as this, I would have to obtain a letter of cooperation from either each individual sorority, or from the governing body of sororities on campus, the Panhellenic Council. After reaching out to the presidents of each sorority as well as the president of the Panhellenic Council, I decided to try to acquire this letter from the president of the Panhellenic Council, however, this fell through, so in the fall of 2018 I was forced to revise my IRB application to remove the provision where I would directly recruit sorority members at large organizational meetings. Though it was most likely for the best, as it is best to have a wide range of participants from different backgrounds than having a relatively homogenous sample, this significantly delayed my ability to begin recruiting for my research.

Similarly, as my initial phase of recruitment progressed, I had to continue to add different means of recruitment to my study. My original application only included means for me to participate via flier in a local newspaper, which became impossible due to the difficulty I experienced in contacting the organization as well as the financial cost I would have to endure, as I did not apply for funding for this project. For these reasons, I had to amend my initial application to include additional means of recruitment, which further stalled the progression of my research.

Lack of Participation

The largest barrier that I faced throughout this research was a lack of participants. To this day, I have only been able to conduct two interviews, which is nowhere near enough to claim any sort of conclusive findings. I believe that this happened for two main reasons. First, I believe that there was a lack of awareness, both of my study and of endometriosis as a whole. It is certainly more than fair to consider that people simply did not experience my multiple forms of recruitment, and thus never ended up reaching out to participate at all.

On that same hand, I think that many women out there do not know about endometriosis in the first place, even if they are suffering from it. As it is not a widely discussed condition, it is very likely that the majority of this campus has never heard of it. That being said, it is even more likely that many women, even if they are aware of the condition, have not yet received a diagnosis from a clinician, and thus are completely unaware that they even qualify for the study. As I will discuss later in the paper, most women with endometriosis experience a large diagnosis gap, meaning they had to wait sometimes years before they seek treatment and receive a correct diagnosis.

It is also reasonable to assume that women did not participate in my study purely because it was not something they wanted to do. I was unable to provide initial face to face contact, so there is very little incentive for someone to want to participate. I also considered the fact that students are simply busy. For someone with a full course load, time may just be too constraining to participate in a research project such as mine, which could take at least an hour out of their day.

For these reasons, it is no wonder that this research has not progressed in a timely manner. It is important to note, however, that I am still entirely invested in this project. I plan to continue to collect interviews as they become available so that I may one day bring this research to its completion.

Chapter 2

What Is Endometriosis?

Although it is not a disease that has historically had much mainstream attention, endometriosis is a chronic condition thought to affect approximately one in ten women. Affecting females of reproductive age, it is marked by the inappropriate growth of endometrium, the tissue that lines the uterine cavity. When found within the uterine cavity, this tissue is responsible for the normal swelling and bleeding associated with the menstrual cycle. In women with endometriosis, however, this tissue is found outside the uterine cavity. Small, or sometimes even large, pieces of endometrial tissue can be found in the pelvic cavity, diaphragm, and even rarely in the brain and lungs. This tissue acts just as if it were found in the uterus, swelling and bleeding along with the menstrual cycle. Unlike the normal menstrual cycle, where the blood would exit the uterus through the vaginal cavity and out of the body, the blood produced in this process has no means of escape. It is forced to flood the abdominal cavity, or wherever the endometrial tissue may be located. This causes tremendous pain and potentially damaging adhesions (scar tissue) to form inside the body in ways which affect other organs. (“Endometriosis” 2018).

Symptoms associated with endometriosis include, but are not limited to, abdominal and/or pelvic pain and cramping, infertility, irregular and heavy periods, and dyspareunia, or pain with intercourse (Whelan 2007:957). As there is no cure for endometriosis, treatment is largely focused on controlling the woman’s symptoms. The best that clinicians can offer their patients is hormonal birth control to stop the menstrual cycle and thus hopefully prevent future bleeding and pain. Otherwise, some women, if eligible, opt to try surgery, which aims to physically remove the misplaced endometrial tissue. There is no guarantee that this tissue will not grow back (which it frequently does), so this by no means is a curative measure (Raffi & Amer 2011). This method is also at risk of the complications that go alongside any surgery, and may not fully eradicate pain, as it can create scar tissue, which may provide its own source of pain.

Doctors and patients alike refer to it as an “enigma” (Whelan 2007:957), because much is still unknown about this condition. Especially perplexing are its origins, as its etiology remains a mystery. The most widely accepted model for the cause of endometriosis is retrograde menstruation. During normal menstruation, the uterus contracts, pushing the blood and broken-down endometrium through the vaginal canal and out of the body. Sometimes, however, this serum of cells gets pushed upwards and into the fallopian tubes and into the abdominal cavity (RETROGRADE MENSTRUATION 1983). From there, the endometrial tissue can travel throughout the woman until it opportunistically attaches to another part of her body. Once it has attached, it continues to act as endometrial tissue, as it swells and bleeds along with the menstrual cycle.

Chapter 3

Methods

Recruitment of Participants

I recruited my participants via two main methods. First, I hung up physical fliers. Any building on campus which possessed a corkboard for student use received one of my fliers. Each was composed of a complete list of qualifications to participate, as well as multiple pull tabs which contained both my Syracuse University email and my cell phone number. The other main form of recruitment that I used was Facebook. This digital advertisement included all of the same information that could be found on the physical flyer. This was posted to many Syracuse University class Facebook groups to reach the greatest number of students possible.

Qualifications for Participation

To participate in this research, each participant had to meet four main criteria. First, she must be female. It is important to note that for the purposes of this study, I am targeting the biological variables of sex and not gender. Next, she must be between the ages of eighteen and twenty-five, as well as a student, either undergraduate or graduate, attending Syracuse University. Finally, she must have previously received a diagnosis of endometriosis from a medical professional. This information will be only confirmed through self-report, as I will not request the participant's medical records.

Why College-Aged Women?

I chose to focus my study on college-aged women, because there is a lack of research on the topic, despite the frequency of diagnoses in college-aged women. The first reason I chose to focus my attention to this demographic is because there is absolutely no literature regarding the experiences of women in college who have received an endometriosis diagnosis. This major gap in the literature is compounded by the fact that for many women, college is the crucial age for diagnosis. From anecdotal evidence, it seems clear that college is the first time that women learn that they have endometriosis. It is a tad disheartening that Academia would entirely look over such an important point in the timeline of the illness experience.

The Interview

Prior to starting the interview, I ask to meet in a private location of their choosing in order to protect the participant's privacy. There are some questions which tap into some fairly sensitive subjects, so I make it a priority to ensure that each woman feels comfortable to answer these questions if she so chooses. Similarly, I allow her to pick the location, to make sure that she is somewhere she feels comfortable so that location does not add any undue stress onto her.

During the interview, participants will be asked twenty-two questions. The first four questions are regarding general demographics such as age, ancestry, employment, and possession of health insurance. The remaining eighteen questions follow the format of a semi-structured interview. During this time, I ask open ended questions about her experiences surrounding the onset of symptoms and how she knew something was wrong, while probing for who she went to for answers and why. Next, I ask about the diagnosis process and what receiving this diagnosis means to her. This is a very crucial time for many women, so I spend a lot of time talking about her responses with her.

We also discuss her symptoms, how they affect the many facets of her life, and how she chooses to cope with them. For many women the pain associated with endometriosis can be crippling, and for others it may be entirely manageable. This is important to ensure that the full variation of experiences of these women do not go unnoticed. Finally, I ask if she feels that her support network, her friends, family, and clinicians, understand what she is going through and any sort of trauma that she may have experienced. Before the interview is officially completed, I leave some time for her to tell me anything that she feels is important for me to know. This is the most important aspect of the interview, as I do not have endometriosis, so I cannot possibly understand the full experience that it entails. This gives her a chance to fill me in on any especially important or meaningful aspects of her illness that I may have missed.

These interviews last anywhere from thirty minutes to an hour, and are digitally recorded with the participant's written informed consent. I transcribe the recordings myself and delete the recordings as soon as I have finished transcribing them. At the beginning of every interview, I encourage each woman not to disclose any identifying details, however if she chooses to share data that could potentially lead back to her, I exclude it from my copy of our interaction. If at any point she decides that she no longer wishes to continue with the interview, or decides that she rather not answer a question, she is permitted to do so.

Chapter 4

Literature Review

Though there is a significant amount of literature about endometriosis, there are few papers that examine the lived experiences of the women who are afflicted. That being said, the research topic does seem to be gaining more popularity. After digging through the bulk of these studies, a few common themes continue to expose themselves: How medicine fails its patients, the diagnosis gap, enduring pain, and pain with sex.

How Medicine Fails its Patients

Although practitioners have the best of intentions for their patients, it is common for those who suffer from endometriosis to feel belittled by their doctors. This is largely a result of the language used. In scientific fields, it is common practice to attempt to use the simplest language possible, though sometimes this may not be the kindest or most human-centered approach. Put plainly, this style of language serves to limit the experience of the patient and remove context from the condition from which she suffers. As has been pointed out in the Journal of Midwifery & Women's Health, "this is a problematic approach to take because it removes any meaning of the suffering that these women are forced to experience on a daily basis" (WOMEN'S LIVED EXPERIENCE WITH ENDOMETRIOSIS ASSISTS CLINICIAN SENSITIVITY AND AWARENESS 2004).

There is more to pain than just the physical sensation. It limits one's ability to be productive, participate in activities that bring pleasure, and interact socially. Even though a patient's symptoms may not be considered particularly severe, her life may be severely impacted nonetheless. In the medical office, however, these contexts are not given much attention, because, "the medical concern regarding pain is generally the site and level of pain, which is usually gauged by pain scores, but for a woman with endometriosis the duration and quality of pain are also of major importance in determining her ability to function and maintain social relationships," (Denny 2009:991). There is more to the chronic pain experience than just the pain itself. In not considering the contexts which women with endometriosis live their lives, clinicians fail to receive the full picture of the condition.

Finally, medical professionals regularly fail those who suffer from endometriosis as they often totally dismiss the pain the woman is experiencing as not real. Women are expected to endure menstrual pain, and those that cannot are viewed as having failed in some way. Often, this failing is given psychological origins. In C.E. Jones' dissertation, "The Pain of Endo Existence: Towards a Feminist Disability Studies Reading of Endometriosis," she argues that, "clinicians. . . often interpret endo pain as psychosocial, arguing that those with endometriosis catastrophize their symptoms" (Martin et al. 2011). Rewriting pain as psychological suggests that those with endo are hysterical, denies them necessary medical intervention, and reduces social support," (2016:4). When clinicians deny the experiences of their patients, it compounds the suffering that they are already experiencing.

The Diagnosis Gap

Though gynecologists and general practitioners do their best to identify and diagnose endometriosis at its earliest onset, this is difficult for a physician to distinguish between a very painful, but otherwise average, period and a more serious underlying issue. Similarly, it is very common for endometriosis to be misdiagnosed, as there are many other disorders which cause pelvic pain, and the only recognized way to definitively diagnose endometriosis is through laparoscopic surgery. This results in what is known as a diagnosis gap, when a patient has to wait an inordinate amount of time before reaching the proper diagnosis. Endometriosis is commonly missed or misdiagnosed as a result of a lack of communication about what is considered “normal” menstruation.

It is hard for young girls or even grown women to know when to look for help, because “normal” menstruation is not easily defined. It is even more complicated when pain, sometimes even intense pain, is considered normal. Looking back on her adolescence, Katrina Rapley articulates just how this complicates girls’ understandings of their bodies. She states, “I just thought everyone had problem periods. I had witnessed my mum with so many problems in her life- she used to get a shot of pethidine in the bum every month via the local GP who would come up. So, that’s what she endured, so when I started getting period pain in my teenage years, I just thought that was fairly normal in fact,” (Markovic & Warren 2008:355). In much of the U.S., periods are equated to pain. Because every woman is expected to menstruate (though not every woman does), every woman is also expected to feel pain. As it is considered normal for a girl to feel pain associated with her period, anyone who complains of this pain is considered to be weak, attempting to get out of obligations, or just looking for attention (Moradi et al. 2014:546).

In the United States, female reproductive health is a bit of an esoteric topic, as it is not discussed openly. Many women therefore endure more pain than they should have to, simply because it is considered an inappropriate topic. As a result, combined with the dismissal of doctors, in the United States, it is common for a woman to wait about twelve years from the onset of her symptoms to receive the proper endometriosis diagnosis (Facchin et al 2018).

Additionally, adolescent girls are at a higher risk of suffering from this diagnosis gap. According to Elaine Denny, “previous research studies indicate that adolescents often wait longer than adults to seek help for their symptoms, believing that what they are experiencing is ‘normal menstruation’; signifying a lack of awareness about endometriosis in this age group,” (Birmingham researcher to explore experiences of endometriosis in adolescent girls 2017). Thus, as a result of a lack of awareness of even the possibility of endometriosis coupled with a lack of information of what is considered ‘normal’ menstruation as a whole, adolescents are doubly affected by this diagnosis gap.

Enduring Pain

Though there is much more to the experience of endometriosis than the pain that a woman goes through, it is the most debilitating symptom. For many sufferers of endometriosis, the pain can be life-altering. According to one woman, “The pain was a crippling disabling pain. It felt like my insides were coming out of my body at times. My legs used to feel like they were lumps of iron. Pain in my lower back. I only remember feeling pain throughout the month, not often free of it, but it was worse at period time normally the first week,” (Huntington & Gilmour 2005:5). This is just one example of the debilitating pain that those without endometriosis will never have to experience, let alone on a monthly or daily basis. Because menstrual pain is considered “normal”, those who have experiences of pain that are abnormal are often considered to be weak or flawed (Denny 2009:989).

Because it is considered normal for a woman to experience pain with menstruation, it is common for girls to push through this pain so that they may continue to be productive in their everyday lives. Even if they wanted to, many women do not have the means to be able to take a day off of work if their cramps are so severe they can hardly stand. According to Rosa Lloyd, a woman with endometriosis, “I don’t think I took myself seriously, and I don’t think anyone else did … I was raised on a farm, [we adopted] a protestant work ethic, if it hurts, go and do something, take your mind off the pain. So it’s work, work, work and you just won’t feel the pain. It’s, like, ‘Like hell you don’t!’, but you convince yourself that that’s normal in the end,” (Markovic & Warren 2008:355). Being able to maintain a full workload even when experiencing pain is the gold standard when it comes to chronic illness, but it does not help the stigma that the patient may still face. As a result of being able to maintain some level of productivity throughout these excruciating symptoms, the people around her may start to discount her pain, erroneously thinking that it could not be as bad as it truly was if she could continue to live her life.

Pain During Sex

Even on top of affecting a woman’s productivity and work life, endometriosis may also have a negative impact on her relationships and sex life. This is because it is not entirely uncommon for a woman with endometriosis to experience pain with sex, also known as dyspareunia. Although many people choose to be a part of loving, committed and fulfilling relationships without sex, for others it can be a deal-breaker in a new relationship. In most cases, this frustration is just as intense for the woman experiencing her pain as her potential partner. For example, one woman blames her inability to maintain a relationship on her ability to have comfortable sex. She states, “I have had dyspareunia my entire life. I have never, ever had sex that wasn’t painful. I’m nearly 30 years old. I want to have sex. I mean it affects my relationships; I’ve never had one that’s lasted longer than six months because guys - you go well - especially when I didn’t know what it was, no one wants to go near that,” (Moradi et al. 2014:8). Not only does she express frustration with feeling unable to participate in sex, but she also seems to blame her body for betraying her in this way.

Dyspareunia in women with endometriosis is not just simple discomfort, for some women it can be just as crippling, if not worse than the abdominal pain associated with menstruation. It is experienced by most women with endometriosis and is sometimes the deciding factor when it comes to searching for a medical diagnosis. One woman explains, “I started to worry when my ex-partner and I got together and the pain during and after sex got that bad that I would just lay in a fetal position for hours afterwards. It got progressively worse to the point where I would actually be crying during and after sex,” (Moradi et al. 2014:4).

This is not to say that all women with endometriosis will struggle to have sex or find romantic partners. One woman describes, although she experiences pain during sex, how she and her boyfriend have learned to cope with her condition. “At first it was a sort of stinging pain when the nodule was pressed during intercourse. Then I had vaginal dryness but I learned how to manage the whole thing because I made my own decision: I want a full life. My partner is also very intelligent and able to handle it during sex,” (Facchin et al. 2018:544). This shows that an endometriosis diagnosis is not a death sentence for a relationship, nor does it mean that a woman who experiences pain with sex may never experience a satisfying sex life. Depending on the severity of the pain associated with sex, and on the understanding of her partner, she may be able to have a fulfilling sexual relationship.

Chapter 5

Endometriosis in Context: Theoretical Framework

Liminality

Liminality refers to the space between the binary. For example, when a person stands in a doorway, she is neither in one room nor the other, but somewhere in between. This concept can also be applied to women who suffer from endometriosis. This is because chronic illness is a liminal state. Sickness is the condition which exists between the binary of life/health, and death (Jackson 2005). It is not a state which people are meant to maintain, and most people only experience it on a temporary basis. According to Talcott Parsons, being sick is considered socially deviant as one is not required to participate in normally expected tasks, but only under the condition that the sick person do everything in her power to become well again and reenter society (Ablon 1981). Marja-Liisa Honkasalo expands upon this, as “chronic illness- by its very existence- defies the definition of illness as a temporary and treatable departure from normal functioning” (2001:320). This puts people who suffer from a chronic illness like endometriosis in a difficult position. Because the illness is chronic, there is no hope for the sufferer to become healthy again, which forces the sick person to exist within this space that is neither here nor there.

“Matter out of Place”: Endometriosis on its own is quite literally, as Mary Douglas puts it, matter out of place. She states, “Dirt is the byproduct of a systematic ordering and classification of matter, in so far as ordering involves rejecting inappropriate elements,” (Douglas 2003). It is tissue that grows where it should not, and thus defiles the body which it lives within. In the correct location there is no negative connotation, but as soon as it travels outside its ordered space, endometrial tissue becomes dirt. In this way, endometriosis is the presence of liminal tissue, defying our schema of the body.

Continuing this application of Douglas' theory, it is not hard to see how endometriosis is polluting. As stated previously, as misplaced endometrial tissue swells and bleeds, it causes chaos within the body. The release of blood into any closed body cavity can be disastrous, as it produces significant amounts of scar tissue which pull on and damage the organs associated with this tissue and produce significant pain.

The women that suffer from endometriosis also occupy this classification of "matter out of place". This is the result of her chronic illness placing her in an ambiguous category. This has the potential to be quite damaging to the woman, as this ambiguity is associated with pollution. Douglas argues that when people or objects fail to fall within certain culturally important categories, they are seen as being polluting to those who exist within those categories (Jackson 2005). This may cause her exclusion from certain spaces. For example, as a sufferer of chronic pain, she may be excluded from being the type of patient that physicians truly want to help. This is because those that suffer from chronic pain "shift back and forth between regions inhabited by innocent sufferers who are unquestionably entitled to medication and regions inhabited by manipulative drug addicts, liars, and criminals," (Jackson 2005).

"Betwixt and Between": Victor Turner, while studying the rituals of the Ndembu people in Zambia, produced a slightly different, yet just as applicable notion of liminality. By his definition, people who occupy liminal spaces within society move "through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial," (Turner 1969:95). If one applies the Parsonian model of the sick role, she may see that the sick person is able to move outside the bounds of normally expected behavior within society. She is not expected to function as a productive member of society; however, she may also be excluded from certain spaces. Turner shows in this way how people who cannot be neatly classified may fall through society's cracks.

Invisibility and Chronic Illness

Liminality on its own creates invisibility. This is because, "as members of society, most of us see only what we expect to see, and what we expect to see is what we are conditioned to see when we have learned the definitions and classifications of our culture," (Turner 1967:95). When society can no longer place a person into the tidy little boxes they use to classify the world, they no longer know how to interact with that person. This makes people uncomfortable. It is easier to look away and pretend whatever does not fit into discrete categories does not exist than to reconstruct one's schema of the world.

Additionally, for the women with endometriosis, there is no outwardly visible sign of what they are experiencing. Their affliction is invisible, which may contribute to their experiences being invalidated by those who are not experiencing it. In her 1981 paper, "Stigmatized Health Conditions", Ablon states that "(s)ome illnesses are more biophysically discrete or identifiable, thus more obviously absolving the bearer from obligations or fault because they are objectively visible, provable, and thus more easily sanctioned than are others with a more significant social component." Endometriosis cannot be seen with the naked eye, people fail to grasp the severity of what women may be going through. This can lead to the trivialization of their illness experiences.

Similarly, people who suffer from invisible chronic illnesses such as endometriosis may be entirely written off. Because there no visible signal that allows one to understand the pain that another person is experiencing, it is easy to assume that they may not be in pain at all. In his book, *Illness Narratives*, Arthur Kleinman states, "if there is a single experience shared by virtually all chronic pain patients it is that at some point those around them- chiefly practitioners, but also family members- come to question the authenticity of the patient's experience of pain," (Kleinman 1998:57). Though this can be applied to anyone suffering from a chronic illness, it is especially true for those who experience chronic pain, as is the case for women with endometriosis.

Stigma

Erving Goffman defines stigma as when a society rejects an individual based on the possession of some negatively associated attribute (1963). For women with endometriosis, both the liminality and invisibility of their condition serve to stigmatize them. This is true both inside the context of medicine and in society as a whole.

Even if it is not something one faces on a daily basis, when doctors stigmatize their patients it can be quite debilitating. Factors such as liminality and invisibility make it easy for medical practitioners to blame their patient or suggest it is all in her head, as it is impossible to simply qualify the pain another person, especially when there is no readily apparent sign of their condition. Due to the invisibility of endometriosis doctors may not enjoy treating women with endometriosis in the first place, as they are likely to be seen as more trouble than they are worth, or a "pain" for the doctor (Jackson 2005).

To ignore the painful experience of endometriosis is entirely unproductive towards the management of this chronic illness and is damaging to patients. It makes the patient feel as if she is the problem and therefore not worthy of medical care. When doctors dismiss the experiences of their patients, their patients feel stigmatized. They are looked down upon for "overreacting" to pain that their doctor may not believe exists at all. In this way, those that suffer from a chronic and painful illness such as endometriosis fail to fit the mold of a "good" patient.

Chronic illness is also stigmatizing because it is socially disrupting. It changes the ways in which people interact with the world. First and foremost, this is because those who experience chronic illness are unable to interact with society in the expected way. The United States can be considered meritocracy, in that people are assigned value based on their ability to be productive. Most people are not stigmatized as a result of illness as they usually recover.
This is because "illness temporarily excuses nonparticipation in social productivity, but the moral responsibility of patients is to work to get better so they can resume normal functioning" (Hay 2010). It is okay to be temporarily unproductive, if one has good reason, so long as she does everything in her power to return to productivity. When she cannot, however, she is devalued and therefore stigmatized.

The only way for someone to maintain their status within society, therefore may be to act as if there is no illness. There are countless stories of how people despite all odds conquer their chronic illness, whether it be how Steven Hawking managed to be perhaps the most famous and influential scientist of modern day even with his battle with ALS or Lady Gaga's incredible fame despite her fibromyalgia. This is the expectation for people who suffer from chronic illness. They are expected to embody what Cameron Hay has deemed the “John Wayne Model,” which is a “pathway or strategy for coping with illness that urges stoicism, independence, courage, and grit to continue to meet all normal societal demands,” (Hay 2010). This is simply not possible for all people, and when someone cannot achieve this level of productivity, people respond negatively. In the United States, there is no excuse to not be a productive member of society. Therefore, those who are forced to stay in bed all day as a result of crippling pain are heavily stigmatized.

Regardless of her experience or abilities, a person’s social roles are inextricably tied to her sense of identity. When she cannot fulfill these social roles as a result of her illness, her identity is called into question, as is her position within society. According to Hay, “in a meritocracy, incapacity is equated with moral liability,” (2010). With this moral liability comes stigma, which shows how the liminal state which endometriosis produces, along with its invisible effects, serves to stigmatize the women who suffer from it.

Chapter 6

Direction of Future Research

Introduction to Phase 2: Interviews and Analysis

As mentioned in my introduction this was the first phase of my research project, which included receiving IRB approval, initial recruitment of participants, and an in-depth analysis of the current literature. I have also included the application of anthropological theory to contextualize Endometriosis. As it stands, this is only a partial work and should be read as such.

In the next phase of my research, I will focus on completing three main objectives. First, I will finish conducting semi-structured interviews with my participants. Thus far, I have already conducted two interviews with two participants. As I continue to gain access to participants, I will continue to conduct these interviews. By the end of this process, I hope to have obtained at least fifteen participants, optimally more, so that I may produce an in-depth review of the lived experiences of these women. I wish to complete as many interviews as possible, as the larger the number of participants, the more applicable the results become to the larger population outside of Syracuse University.

If I fail to acquire a large sample, it will slightly alter the format in which I will describe my results. Instead of producing a large list of shared experiences and their summary, I will instead deeply examine the few experiences which I was able to obtain. With this information, I will condense these experiences into one narrative. The lived experiences expressed in this narrative will be used to describe some common themes among this age demographic. This method is commonly used in anthropology to both obscure the identities of the participants, as well as allow the inclusion of significant themes that may only be experienced by a portion of the participants.

The next step in this phase is to transcribe all of the recorded interviews by hand. This is done to protect the identity of each of my participants. By doing so, I am able to remove any data that could potentially be traced back to a singular participant. The transcription process also allows me to interact more intensely with the data obtained through the interview. After transcribing, each audio recording will be deleted, which also protects participants from recognition via their voice, in the unlikely scenario someone gains access to the raw data.

Finally, the last step in phase two is to analyze these results. This analysis will result in a much larger paper to be published. This is important, as it will at the very least be the first step in closing the gap in the available research on women with endometriosis. As of right now, there has been no study done on the lived experiences of college-age women living with endometriosis. This paper will hopefully start the conversation on this important phase of the lived experience of this illness and result in many more studies aiming to further understand this subject.

Suggestions for Future Research

For my colleagues who wish to continue what I have started, I suggest that she broaden her search criteria. I have struggled with a lack of participation, and I believe this is in part due to women not yet receiving any diagnosis. If one instead looks to include women who have only recently received their endometriosis diagnosis, she will most likely significantly increase the number of women eligible to participate while still being able to assess the initial experiences of women during this tumultuous time in their life.

I would also like to ask the medical community to look at the experiences of treatment. I have come across countless records of women suffering as a direct result of Depo Provera, a birth control which is injected into the bodies of women. This can induce menopause, which is undesirable, especially for young women. There is much research to be completed on effective treatment for this disorder.

Chapter 7

Conclusion

Clearly, endometriosis is a condition with many facets. On the surface, it is a medical condition characterized by chronic pain that mainly affects women of childbearing age. Digging deeper, it is a disease which affects a woman's ability to work productively, live comfortably without pain, and maintain social relationships. It is complicated by the cultural contexts surrounding menstruation, which categorize female bodily functions as inappropriate topics for conversation. The esoteric nature of female reproductive health, and the social expectation of pain during menstruation may cause women to hold on and endure the pain when they could instead be receiving medical treatment for their condition. This, in turn, leads to an extended diagnostic delay which prevents women from receiving helpful treatment to improve their quality of life in a timely manner. Even after receiving a diagnosis and treatment, there is no cure for this condition.

Applying anthropological theory to endometriosis can demonstrate how the pain associated with the condition is compounded through psychological suffering. Through the exploration of the liminal aspects of endometriosis, one can see how chronic illness exists between normal categories. This mixing of categories makes people uncomfortable, and often leads to the stigmatization of the sufferer. Similarly, the invisible nature of the chronic pain associated with endometriosis often leads to the devaluation of the experience of the sufferer, which produces further stigma.

There is still much work to be done in terms of examining the lived experiences of women who have received an endometriosis diagnosis. The most prominent of these being the major gap in the literature describing the lived experiences of adolescent women. The vast majority of papers about the lived experiences of women with endometriosis focus on women in their thirties and forties. I believe that it is important to target the experiences of young women of college age, who have just recently received their endometriosis diagnosis, as they are at a crucial moment in their understanding of their condition. Without knowledge surrounding this time of diagnosis and coming to terms with her condition, it is impossible to gain the full picture of the experiences associated with the condition. My current research will start filling in some of these missing pieces.

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