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Voices of Endo: Cultural Factors Influencing Delayed Diagnosis of Endometriosis

By

Arline Votruba

Claremont Graduate University
2023

Approval of the Dissertation Committee

This dissertation has been duly read, reviewed, and critiqued by the Committee listed below, which hereby approves the manuscript of Arline Votruba as fulfilling the scope and quality requirements for meriting the degree of Doctor of Philosophy in Cultural Studies.

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Abstract

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An estimated one in ten people born with internal reproductive anatomy, meaning the vagina, cervix, uterus, fallopian tubes, and ovaries, live with endometriosis, which is about 200 million people worldwide. Endometriosis is a disease in which the growth of endometrial-like tissue grows around the reproductive organs, rectum, bladder, or throughout the body in places it does not belong. Endometriosis often leads to devastating effects such as painful, prolonged menstruation, nausea and bowel issues, pain that radiates down the legs, and it is a leading cause of fertility challenges. Endometriosis is diagnosed through laparoscopic surgery, in which a surgeon inserts a small camera into the abdomen to identify abnormal tissue growth. Despite the prevalence of endometriosis, research shows that there is an average ten-year delay to diagnosis even though diagnostic technology is widely used in the United States. Scholarship about endometriosis has predominantly focused on medical diagnosis and treatment options and the public literature about endometriosis has presented self-help recommendations for readers to manage their illness individually. However, less academic or public attention has been paid specifically to the relationship between endometriosis patient and healthcare practitioner to uncover how medical transactions demonstrate why there remains an average ten-year delay in diagnosis of endometriosis. My dissertation is the first scholarly application of a cultural studies analysis to explore why there remains a ten-year delayed diagnosis of endometriosis in the United States. This study combines interviews and autoethnography to explore what the experiences of people with endometriosis demonstrate about how cultural factors contribute to the delayed diagnosis of endometriosis. My project centers the voices of people living with endometriosis, including my own, to shift the perception of what is determined medical knowledge, by positioning qualitative interviews with patients as valid medical research. I conducted interviews with eighteen people living with endo in the United States whose diagnosis took eleven- and one-half years on average. The findings of this case study of endometriosis patient-experiences builds upon literature in the medical humanities, feminist & gender studies, as well as cultural studies. This dissertation analyzes major themes that emerged from the data. For example, many participants said that their doctors normalized menstrual pain by dismissing their reports of painful menstruation, which represent how common cultural perceptions of womanhood inhibit recognition of endometriosis symptoms as medically significant by doctors. Additionally, because in the United States menstruation is taboo, participants reported how they adopted a coping strategy to publicly hide their symptoms in a phenomenon I coin as performing wellness. Performing wellness is a term I define in reference to the phenomenon of people acting healthy or pretending to be in a state of well-being while they are simultaneously hiding symptoms of underlying invisible illness to publicly censor their limitations from their friends, family, or coworkers. Finally, participants shared how their self-education and self-advocacy served a critical role in reaching their diagnosis, which indicates undue cultural pressure for individuals to manage their health issues alone. This study shows that while medical diagnosis of endo is standardized, the process of diagnosis is fundamentally impacted by cultural ideas entrenched in sexist perceptions of menstruation. The findings of this research begin a deeper engagement with the cultural implications of delayed diagnosis, which is a starting point to establish a pathway towards a medical model that will not allow others to suffer in anguish for a decade.

Dedication

This dissertation is dedicated to all persons—past, present, and future— living with endometriosis. May these pages offer you understanding, validation, and inspiration to pursue the care you ultimately deserve until you achieve it.

Acknowledgements

In gratitude, this project would not have been possible without the time, energy, and participation of the eighteen people living with endometriosis who graciously shared their time and their stories with me. I appreciate you sharing your voice to advance the knowledge we have of endometriosis. Your stories have all shaped the outcome of this project and given nuance to what life with endo means. Thank you for your time. Additionally, I thank Maggie Bowyer, a creator who wrote poetry about her endometriosis experience and generously permitted me to feature her works throughout the chapters of this dissertation.

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Prologue

Lying in bed clutching my side I wondered what was going on inside of me. Why am I feeling so much pain? How is it possible that I have bled more days this month than not? When will this stop? Will this ever stop? Worries such as these frequented my thoughts during the years that I suffered from undiagnosed endometriosis. Although I eventually reached a diagnosis at age twenty-three and received supportive treatment at age twenty-six, the years of frustration, concern, and agonizing pain have altered my life in permanent ways.

It took a long time for me to get comfortable talking about my menstrual symptoms with others. At an early age, it was made clear that menstruation was something I should hide. Sneak the tampon up my sleeve while going to the bathroom at school, pretend that my cramps are a stomachache when I asked to go see the nurse, just do not mention my period. I struggled with heavy and painful periods from the time I reached menarche at age twelve.

My periods were never “normal.” My friends would bleed lightly and move about their days as usual, while I would struggle to change my super tampons fast enough to avoid staining my underwear or pants from bleeding through. “You’re on your period again?!” was a common question that my friends would ask in awe, as I bled for fourteen days at a time, with only fourteen days between menses. I bled long, I bled heavy, and I felt cursed. It felt like my period was always there when it was least welcome. Every beach vacation, first day at a new job, or opportunity to go do something fun was accompanied by my period. I had tampons stashed in every purse, backpack, jacket, and drawer. Once I started driving, there was always a reserve in my vehicle because I needed to be prepared for an unexpected or heavy flow at any moment.

When it came to my menstrual troubles, going to the doctors always elicited a blend of hope and fear. Eager to get to the bottom of my suffering, I knew I had to tell my doctor just how fatigued I felt, how debilitating my pain was, how long my menstruation would last, and I could not hide how detrimental the daily suffering was to my capacity to be. Appointment after appointment the doctors would always say that “This is normal,” or “Periods are just worse for some women.” The only treatment offered to me from age twelve until twenty-two was hormonal birth control. I tried numerous kinds, but even if it seemed to help for a month or two, eventually I would experience breakthrough bleeding and be back to my pattern of two weeks bleeding each month.

The unknowingness associated with my symptoms transitioned into a deep sense of loss. I had lost myself, my tenor for optimism, the enthusiasm that once punctuated my demeanor had fizzled away with my last bits of energy. The cramps ripped me apart. I felt like I was being tortured by my body. How could this be happening? Fed up with my body by the time I reached my twenties, I could no longer self-censor the impact that my menstrual life was having on my daily experiences. I started to be more vocal about what I was going through publicly. I told my mom, partner, and friends about the pain and struggle of my period. I told them that I was suffering, and I was scared. Even though they listened, I felt extremely alone.

When I was twenty-three years old, my primary care doctor listened to me when I suggested that perhaps I was living with undiagnosed endometriosis. After years of being told this was “normal,” I thought I had finally found the golden ticket to relief because my primary care doctor *believed* me. Little did I know that the struggle with symptoms and pain management would continue for years before finally reaching a consistent pattern of painlessness. The primary care physician referred me to a women’s reproduction specialist who promised me a surgery at our first meeting. I accepted the treatment and scheduled a laparoscopy for two months later. I was excited to be treated, but at the time, I did not know that there are different types of endometriosis surgeries with different levels of success. Unfortunately, although the first surgery led me to a diagnosis, it did not prove successful, and my symptoms persisted for several more years.

Living with endometriosis is a burden. It is debilitating, but because it is outwardly invisible, I was accustomed to pushing through and showing up to work or activities on days that I imagine my symptoms would have led others to visit a hospital. I mastered the art of silently taking slow, cleansing breaths to try to calm my nervous system during bouts of painful symptoms while I was working or hanging out with friends. The pressure to be healthy and show up in our society led me to adopt coping strategies. I pretended to be well to keep the burden of my illness to myself.

Endometriosis has shaped the person I am today. Living with endometriosis has made me feel as though there is nothing I cannot manage, because the level of uncertainty and severity of pain I experienced chronically never interrupted my commitment to my goals. However, I do not see this as an accolade. Rather, my perseverance reflects how United States culture trains us to conceive of illness. United States societal expectations assume that one must not be too sick to tend to their obligations, otherwise they are recognized as deficient. In a just world, my suffering would have been more alarming to the doctors I reported it to, I would have been offered time off from work on days I was crying from pain, and I would have had more time to rest and try to recoup my energy leading up to and during my period. Although those opportunities were not available, my privileged position as a White woman with financial support from my parents allowed me to access the top endometriosis care in the northeast United States. My most recent surgery helped to eliminate almost all the pain and symptoms associated with endometriosis that

I once experienced daily. My experience with endometriosis has taught me the value of *access* to good health.

My experiences with endo led me to write this dissertation addressing the very struggle I, alongside so many others, have endured. The more I read about endometriosis, the more fascinated and disturbed I felt by what people were saying, “dismissed for years,” “misdiagnosed,” “mistreated,” and I felt my experiences echoed those I was reading online and in endometriosis books. To generate awareness and reclaim power for those afflicted, I am dedicated to increasing the knowledge we have of endometriosis, because the current trends are not acceptable. Recognizing that my experience is not unique, rather representative of patterns of delayed diagnosis, I decided to speak with people living with endometriosis to extend the current research we have on people with endo’s experiences.

It has been about two years since my second endometriosis laparoscopic surgery. Unlike the first surgery, during which the surgeon burned the endometrial tissue, my second surgery was done through deep excision, which is considered the gold standard of endometriosis care. I am in awe at how my body has transformed since the second operation. Although I still experience pain during ovulation, the chronic back pain that once made daily life a struggle, the agonizing surges of pain in my lower left abdomen that would often linger as an ache, and the nausea that would leave me unable to rest, have all subsided since the procedure. I am a lucky one. I found excellent surgical care before my endometriosis progressed to a later stage- and at the young sprite age of twenty-six. Unlike most folks in my position, I am here to tell the tale of renewal, relief, and overcoming the burden of such a diagnosis as endometriosis. I am proof that diagnosis and treatment are possible. I am proof that surgical intervention can have transformative outcomes. Yet, it remains so out of reach for so many. The possibility of relief from endo is limited by inaccessible doctors and expensive procedures. I was only able to access elite medical care for endometriosis because of the financial support I received from my parents. I only learned that deep excision surgery would be helpful because of my access to education and my accompanying research habits.

My health is a privilege. I want it to be a fundamental human right that others are given the justice to access. In another world, other life circumstances, this disease could have determined the future of my reproduction for me- it could have led to the loss of function of organs, it could have led to an addiction to pain meds, or another combination of self-medication strategies to cope- but I have been given an opportunity, and with it, I feel the urgency to uncover the stories of others in a similar, or dissimilar, position, to help navigate why it continues to take so long for endo warriors to learn who they are and who their community is.

This dissertation project which poses the question of why it takes an average of ten years for people with endometriosis to be diagnosed in the United States was animated by my encounter with the delayed diagnosis of endometriosis, of which I suffered for eleven years.

Terminology

Endometriosis/endo:

Endometriosis and endo are used interchangeably throughout this dissertation to refer to the disease in which tissue like the endometrial tissue typically located inside the uterus grows outside of the uterus. The growths of endometrial-like tissue around the reproductive organs, chest, lungs, and other places throughout the body produce scar tissue or form adhesions that can constrict organ function. Endo is a progressive disease, so if left untreated the tissue will continue to spread throughout the body.

People living with endo:

In the following, I attempt to degender language referring to those who are living with endometriosis to reaffirm the diversity of genders that endometriosis patients might identify with. People living with endo broadly refers to people who are experiencing symptoms or fertility challenges because of endometriosis, whether they have been diagnosed or not.

People with internal reproductive anatomy:

I have selected to refer to people with internal reproductive anatomy to signify persons born with a vagina, cervix, uterus, and fallopian tubes. The intentional use of genderless language to refer to reproductive biology is an attempt to reject the common tendency to misuse sex and gender interchangeably, often seen in medical and public discourses.

Medical gaslighting:

The process through which a healthcare professional downplays or dismisses the symptoms a patient is experiencing and instead tries to convince the patient that the symptoms are not caused by underlying illness or that perhaps, the patient is imagining, fabricating, or exaggerating their symptoms.

Fertility challenges:

Rather than using the common term “infertility,” I have selected to say fertility challenges whenever possible to refer to difficulties faced when trying to get pregnant. Infertility is not an adequate term for most instances of fertility challenges because it forecloses the idea that pregnancy is possible. Although people who face difficulty conceiving often undergo treatments or assistive therapies, their fertility is not necessarily defunct. Thus, my use of the term fertility challenges leaves open the possibility that with proper care, even folks struggling to get pregnant might find success.

Introduction

Globally, it is estimated that there are about 200 million people living with endometriosis.[1] Estimates indicate that ten percent of people with internal reproductive anatomy in the United States live with endometriosis.[2] Someone with endometriosis might experience various symptoms not limited to painful, prolonged, and heavy menstruation, pain with intercourse, bowel issues, pain between periods, or fertility challenges. Although symptoms vary from person to person, untreated endometriosis can negatively impact one's ability to conceive naturally or can cause damage to internal organs when left to spread without medical intervention. Further, the symptoms of endometriosis are often debilitating to those living with the disease. However, endometriosis research indicates that it takes an average of ten years between the onset of symptoms and medical diagnosis of patients with endometriosis in the United States.[3]

Menstruation occurs when endometrium builds up in the uterus and is shed during a monthly cycle. Cyclical shedding of endometrial tissue is part of the body's biological function. With endometriosis, endometrium grows waywardly in spaces such as around the ovaries, fallopian tubes, bladder, rectum, and in some cases the diaphragm or in the lungs.[4] Endometriosis growths create scar tissue called adhesions that cannot exit the vagina like with a monthly period, resulting in internal bleeding and inflammation. The sites of abnormal endometrial growths respond to hormonal shifts in the body like endometrium and thus the growths act as sites of

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[1] Tamer Seckin, *The Doctor Will See You Now: Recognizing and Treating Endometriosis*, (Nashville, Tennessee: Turner, 2016), 18.

[2] Andrew S. Cook, *Stop Endometriosis and Pelvic Pain: What Every Woman and Her Doctor Need to Know*, (Calif.: Femsana Press, 2012), 40; Nancy Arden McHugh, *The Limits of Knowledge: Generating Pragmatist Feminist Cases for Situated Knowing*, (Albany: State University of New York Press, 2015), 17.

[3] Cook, *Stop Endometriosis and Pelvic Pain*, 26; Seckin, *The Doctor Will See You Now*, 18; Kate Seear, *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*, (Farnham, Surrey, England: Ashgate, 2014), 8.

[4] Sharon Deevey, "Endometriosis," (Medical Reference Services Quarterly 24, no. 1, 2005), 68.

micro periods.[5] The growth of endometriosis lesions and adhesions can constrict organ function, cause fertility challenges, and create long-lasting damages if left untreated.

A medical diagnosis of endometriosis can only be achieved through laparoscopic surgery in which the surgeon inserts a laparoscope through the bellybutton or abdominal incisions to visualize and excise endometrium lesions to be sent for testing by pathology. Therefore, medical practitioners often attempt to rule out all other options before scheduling a surgery. Endometriosis is often misdiagnosed because endo symptoms mirror those of interstitial cystitis, irritable bowel syndrome, and pelvic adhesions,[6] which contributes to delayed diagnosis.[7] However, misdiagnosis is only one area contributing to the delay in diagnosis of endometriosis. This dissertation serves to supplement the medical research about endometriosis through a broader engagement with how the process of medical diagnosis of endometriosis is entangled with and overdetermined by cultural constructions of identity.

As common as other well-known illnesses such as diabetes or asthma, endometriosis impacts about 200 million people with internal reproductive anatomy between the ages of fifteen and forty-nine years old.[8] Yet, it takes an average of ten years between the onset of symptoms and medical diagnosis of patients with endometriosis.[9] During the decade-long delay to diagnosis, people often experience debilitating pain, fertility challenges, or find themselves wasting time pursuing ineffective treatments due to misdiagnosis. In the United States, annual costs of endometriosis have been estimated at about $22 billion.[10] With only about one-hundred trained

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[5] Deevey, "Endometriosis," 68; McHugh, *The Limits of Knowledge,* 17.

[6] Caroline S. Zeind, *Applied Therapeutics: The Clinical Use of Drugs*, (Philadelphia: Wolters Kluwer, 2018), 1005-1027.

[7] Seckin, *The Doctor Will See You Now,* 73.

[8] Endometriosis.org. "Facts about Endometriosis " Endometriosis.org." Endometriosis.org. Accessed April 11, 2021. http://endometriosis.org/resources/articles/facts-about-endometriosis/.

[9] Cook, *Stop Endometriosis and Pelvic Pain*, 26; Seear, *The Makings of a Modern Epidemic*, 8.

[10] Seear, *The Makings of a Modern Epidemic*, 8.

endometriosis specialists worldwide, most procedures to diagnose and treat endo are completed by general reproductive surgeons.[11] The high cost of surgery poses a challenge for many seeking diagnosis, as surgical costs range from about $5,000 to $35,000.[12] The current state of endometriosis delayed diagnosis leads thousands of people living with endometriosis debilitated for years without treatment or an explanation for their condition. It seems that it is no coincidence that although endometriosis is common, there are barriers to diagnosis, likely tied up with the direct relationship between endometriosis and menstruation. Despite the prevalence of endometriosis, the disease continues to be widely unrecognized, underdiagnosed, and a cause of physical and mental strife for those afflicted. While some research cites misdiagnosis as a factor contributing to the delayed diagnosis of endometriosis,[13] less attention has been paid to how cultural ideologies and conceptions of gender have created barriers for people with endometriosis seeking diagnosis. The delayed diagnosis of endometriosis is unacceptable, given the available technology and standardized approaches to diagnosis.

Although scholarship and research about endometriosis exist, there has been little work specifically developed through the perspectives of those living with endometriosis grounded in the cultural studies or feminist tradition. Within medical literature, the tendency is to evaluate people with endometriosis as subject, rather than expert, which demonstrates a power imbalance in the process of knowledge production. Alongside the initiative to uncover why there remains a ten-year delayed diagnosis of endometriosis in the United States centered throughout this dissertation, I also evaluate methods for medical knowledge production to develop an alternative

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[11] Seckin Endometriosis Center, "Why Is It so Hard to Find an Endometriosis Specialist?" (*Seckin Endometriosis Center*, June 25, 2022), https://drseckin.com/why-is-it-so-hard-to-find-an-endometriosis-specialist/.
[12] Amber Blackburn, "Out-of-Pocket Costs: Laparoscopic Surgery for Endometriosis," (Endometriosis.net, July 9, 2020), https://endometriosis.net/clinical/cost-laparoscopy-surgery; Shruti Chopra, "How Much Does Laparoscopic Endometriosis Excision Surgery Cost?" (All Things Endometriosis & More, September 8, 2021), https://allthingsendometriosis.com/how-much-does-laparoscopic-endometriosis-excision-surgery-cost/.
[13] Seckin, *The Doctor Will See You Now*, 80; Cook, *Stop Endometriosis and Pelvic Pain,* 13.

approach to learning about disease. I employ feminist methodology, such as the use of standpoint epistemology, to provide space for the people living with endo to participate in this research. Through standpoint epistemology, this dissertation gathers knowledge of endometriosis from those who live with it to model new forms of knowledge production that position people with firsthand experience as experts of their disease. In this dissertation, I position people with endometriosis as experts, meaning that they are credible sources to report accurate knowledge about endometriosis based on their bodily experiences living with the disease.

Further, this project is grounded in cultural studies through the explicit examination of the power dynamics between endometriosis patient and doctor relationships to better identify ideological constraints on medicine. Since the people with endometriosis that I interviewed for this dissertation have lived with endometriosis, they have a deeper understanding of the intersections between their bodily experiences of symptoms related to endometriosis and their external relationships with medical professionals. Based on their lived experiences, I qualify the people with endo that I interviewed as experts regarding endometriosis, as a disruption to the dominant trends in endometriosis research. Throughout this dissertation, I examine why there remains a ten-year delayed diagnosis of endometriosis by speaking directly with people who live with the disease to uncover whether cultural factors related to their unique identity has inscribed meaning within their medical encounters, which have impacted their diagnostic journey.

The trends of delayed diagnosis of endometriosis support that endometriosis is not only a distinct medical conundrum, but that examining endometriosis delayed diagnosis provides a case study that further engages what we know about the intersections of gender and medicine. Uniquely, endometriosis is a disease deeply informed by gender, which presents an opportunity to learn more about how cultural ideology influences medical experiences for those with endometriosis. Thus, the overarching question guiding this dissertation asks how the firsthand accounts of people with endometriosis can offer insights about why there remains a ten-year delay to diagnosis in the United States. Specifically, because endometriosis effects people with internal reproductive anatomy, the disease is culturally tied to conceptions of womanhood. Widespread ideas of womanhood and the stigmatization of menstruation as taboo in the United States serve as an entry point for the examination of endometriosis delayed diagnosis as a cultural studies case study concerned with issues of reproductive justice. Thus, this dissertation also engages the question of how a case study of stories from people with endo reflect the values embedded in United States medical practices and might deepen our understanding of what the diagnostic delay can teach us about dominant ideological constructions embedded in the United States medical industry. Since the trend of delayed diagnosis of endometriosis leaves people suffering for an average of ten years without awareness of what their disease is or how to properly treat it, I conceptualized this dissertation by asking more broadly what it is that doctors, patients, and the public should know about endometriosis and imagining what could happen if endometriosis becomes a widely recognized disease. Such questions might yield answers that help move us closer towards medicine grounded in a politics of reproductive justice.

The purpose of this research is to examine patient narratives to develop a sense of their experiences to find out why people living with endometriosis struggle for so long to receive a diagnosis and subsequent treatment. Identifying trends in patient accounts might indicate cultural factors that impact the road to diagnosis for endometriosis patients to help readers understand the role that medical professionals and cultural stigmatization play in endometriosis diagnosis. Ultimately, this project culminates with an identification of how patient stories about their endometriosis experiences can teach us about how culture and medicine converge to produce the disproportionate delayed diagnosis of people living with endometriosis in the United States. Examination of endometriosis delayed diagnosis throughout this dissertation is rooted in a mixed methodology including both interviews and autoethnography. The framework and methods for this research are engrained in a feminist reproductive rights consciousness committed to a reproductive justice praxis, meaning that the results of this study are intended to inform new approaches to the conceptualization and practice of endometriosis diagnosis.

This transdisciplinary dissertation is grounded in lines of inquiry emerging from multiple areas of concentration: cultural studies, feminist and gender studies, medical humanities, and epistemic oppression discourse. The purpose of this cultural studies analysis is to offer a qualitative case study to investigate how the experiences of people with endometriosis provide insights about why it takes an average of ten years for folks to be diagnosed with endo in the United States. Since cultural studies is an inherently transdisciplinary field, this dissertation combines feminist and gender studies methodologies, epistemic injustice theory, and contributes to medical humanities discourse through the examination of a medical problem through a humanities lens. Medical research on endometriosis has yet to explain why there remains a ten-year delay to diagnosis for endo, despite the prevalence of endo in one in ten persons with internal reproductive anatomy. This dissertation attempts to uncover why there remains a ten-year gap through a cultural studies analysis that examines closely the encounters between patients with endo and the medical establishment. Focusing on the stories from persons with endo and welcoming them to report their experiences provides a unique opportunity to learn from those living with the disease. Allowing people with endo to speak for themselves, this project uncovers ideological constraints to endometriosis diagnosis and care, culminating in discussions about how cultural factors shape the experiences of people seeking an endometriosis diagnosis.

Engaging with the power dynamics at play between patients and their doctors, or sick persons and the medical establishment, the undercurrent of this project is a cultural studies analysis of how endometriosis diagnosis presents a case study of medical power influenced by cultural ideologies. The analysis of patient accounts is grounded in a cultural studies reading of how the stories from people with endo teach us about the constraints of prevailing cultural ideas. As scholars like Stuart Hall have argued, culture is a place of interpretive struggle. This project will elaborate on how the ideologies that have shaped who has been determined likely to live with endometriosis have been developed through cultural inscription of meaning tied to identity rather than scientifically determined through experimentation. For example, the interviewees' accounts represent that their experiences have been shaped by gendered notions of menstruation. Additionally, as Althusser has argued, media provide a means through which institutions can pass on their agenda without applying physical force, which is represented in my examination of how self-help texts have constructed the identity of persons with endometriosis. A close textual analysis of prevailing literature about endometriosis, which is embedded in the self-help genre, reflect a neoliberal positioning of sick persons as individually responsible for their healing. While this dissertation is transdisciplinary in approach, the grounding framework of analysis comes from a cultural studies perspective.

In addition to cultural studies, this work is closely tied to scholarship in feminist and gender studies. Much of the justice oriented reproductive rights discourse in the United States has been led by women, for women. Publications such as *Our Bodies, Ourselves* have positioned women as responsible for engaging community approaches to education through standpoint epistemology, in which women share their bodily knowledge to spread awareness of reproductive health with each other. This project is similarly grounded in standpoint epistemology, to further what we know about endometriosis delayed diagnosis from the people who have experienced it firsthand. However, the implications of this work will benefit more than just those afflicted with endometriosis.

The work in this dissertation aims to provide useful insights to improve how we develop medical knowledge broadly because, as Shai et al. have argued, "An approach that integrates feminist epistemology and methodology into the study and practice of medicine and strives to understand the complexity of gender can improve the health of both women and men worldwide."[14] Thus, this project aims at a wider intervention within feminist and gender studies by complicating the trend of delayed diagnosis as a product of ideology. I suggest that the case study of endometriosis has implications that can advance medical epistemology that serves all genders. This study exposes how biases informed by gendered ideology limit access to adequate diagnosis and treatment for people with endometriosis, who predominantly identify as women. Thus, this work offers a critique of non-reflexive medical approaches that ignore the ways in which medical practice is overdetermined by ideological partiality. Throughout this dissertation, women are positioned as the primary producers of medical epistemology to reclaim their experiences as experts on endometriosis, which reimagines the boundaries of what is traditionally understood as medical knowledge. People with endometriosis are interviewed through a standpoint epistemology that centers their experience to create deeper understandings about endo.

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[14] A. Shai, S. Koffler, & Y. Hashiloni-Dolev, "Feminism, Gender Medicine and Beyond: A Feminist Analysis of 'Gender Medicine,'" (*Int J Equity Health* 20, 177, 2021), 8.

This dissertation engages with endometriosis as a site where medical knowledge is contested. Young and Kirkman examine women with endometriosis' experiences of navigating knowledge and power with medical experts. Their results substantiate the persistent dismissal of women's knowledge and experience by clinicians.[15] In the study, Young et al. conclude that patients remained wary of their doctors' ability to deny the care needed to improve their condition, stating, "Women navigated knowledge and power within the medical encounter for endometriosis through a complicated dance between their own embodied knowledge and clinical expertise of their doctors."[16] The results of their study point to the patterns of patient-doctor dynamics as a site of struggle, in which patients are told that their symptoms are imagined, while their bodily expertise indicates otherwise. Thus, lived knowledge of people with endo via their bodily experiences delegitimize the dismissal of their symptoms by their doctors. This project furthers the work started by Young and Kirkman to dive deeper into power and knowledge in medical contexts by looking to people with endometriosis, rather than interviewing medical practitioners. Young and Kirkman's work shows how endometriosis represents a site of epistemic oppression, of which my work engages with the theory of epistemic injustice.

Epistemic oppression provides a theoretical framework through which to examine sites of power differentials in knowledge production, which allows a close analysis of how medical knowledge has been conceptualized and the limitations of medical models that dismiss patient reports as scientifically valid. This work draws from the theory of epistemic injustice, a lens through which to evaluate epistemic oppression, in which scholars examine sites where knowledge produced by and for marginalized folks is invalidated or excluded. Through the

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[15] K. Young, J. Fisher, & M. Kirkman, "Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis," (*Feminism & Psychology*, *30*, 1, 2020), 35.
[16] Young et al., "Partners Instead of Patients," 37.

silencing of marginalized knowers, epistemic violence is perpetuated.[17] In this dissertation, I critique the limitations of common trends that position knowledge produced by and for doctors as valid while knowledge produced by and for patients is often dismissed and devalued by doctors in positions of authority. By delegitimizing endometriosis patients as "epistemic agents," doctors discrediting endometriosis patient reports of their symptoms have demonstrated a trend of "eroding their [endometriosis patients'] epistemic authority by indirectly attacking their credibility."[18] If endometriosis patients' knowledge becomes perceived as epistemically viable by medical authorities, we might advance medical epistemology to improve the time to diagnosis for people living with endometriosis. Specifically, examining endometriosis as a case study, my work employs medical humanities frameworks to analyze invalidated sites of knowledge production like patient accounts to advocate for reimagining medical epistemology, centering patient experiences as valuable in the production of medical knowledge.

In "Epistemic Injustice in Medicine and Healthcare," Carel and Kidd suggest that one reason ill persons are vulnerable to participatory prejudices is because "…ill persons are supposed to lack the training and experience needed for the possession of a robust sense of relevance required for the epistemic practices of medicine," and, "…are typically regarded as *objects* of, rather than as *participants* in, the epistemic practices of medicine."[19] Positioning people with endometriosis as experts on the disease, I engage an epistemic justice framework to combat the epistemic injustice of the historical dismissal of patients with endometriosis as unreliable informants. My work contributes to a medical humanities reimagination of medical knowledge production in

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[17] Patricia Hill Collins, "Intersectionality and Epistemic Injustice," in *The Routledge Handbook of Epistemic Injustice*, (New York: Routledge, 2017), 121.

[18] Collins, "Intersectionality and Epistemic Injustice," 119.

[19] Havi Carel and Ian James Kidd, "Epistemic Injustice in Medicine and Healthcare," In *The Routledge Handbook of Epistemic Injustice*. (New York: Routledge, 2017), 340.

which people with endometriosis are situated as epistemic agents who hold expertise of their disease based on their lived experience. The case study of endometriosis presented throughout this dissertation might provide a model for research on other diseases with a reportedly long delay to diagnosis.

Medical Humanities: An Endometriosis Case Study

Whereas medical research typically focuses on clinical, laboratorial, or epidemiological questions,[20] the emergence of medical humanities has allowed researchers to explore medical problems using humanities approaches. The major critical trends in contemporary medical humanities are: 1) Applying a humanities approach to study medicine, often in humanities departments; 2) Intervening in medical education with arts and humanities approaches, such as art therapy in medical treatment; 3) Creating artwork for public galleries or museum spaces that engage issues of health and illness, centering the medical.[21] This dissertation aligns closely with the first category because I apply a reproductive justice framework to explore endometriosis as a site for medical humanities intervention. Reproductive justice has positioned itself epistemologically through employing identity politics as an important approach to creating individualized, nuanced knowledge, which provides deeper considerations of how communities are oppressed differently. Reproductive justice frameworks often employ standpoint theory to consider how one is oppressed by another person or institution due to identity characteristics

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[20] The existing endometriosis literature is predominantly located in medical journals and published for medical researchers and practitioners. Literature about endometriosis has been primarily developed through traditional medical methodologies to generate knowledge of endometriosis disease symptoms, causes, diagnostic measures, and treatments. This dissertation is a departure from traditional medical approaches to endometriosis research to engage with how the experiences of people with endometriosis can teach us more about the cultural construction of identity as it relates to the disease.

[21] Alan Bleakley, *Medical Humanities and Medical Education: How the medical humanities can shape better doctors*, (New York: Routledge, 2015), 40.

such as their gender identity, race, religion, or class in addition to other aspects of identity.[22] Throughout this project, I examine the firsthand accounts of people with endometriosis to identify patterns in their reports that indicate cultural and ideological constraints to their search for diagnosis.

The need to reexamine endometriosis through the medical humanities is marked by the shift in power dynamics between patients and doctors. During the mid-to-late twentieth century, an increase of medical science and technology led to an "… alteration in the power structure in the physician–patient relationship with the physician becoming the 'expert.'''[23] The transition towards a medical model in which physicians are considered experts deepened the power dynamics between patient and doctor, leading patients to trust their doctors as authorities on medical matters. The shift towards physicians as experts also led to trends in which patient accounts and reports were not seen as medically significant. Thus, the current United States medical model assumes that doctors are the experts within medical encounters in what has become a $3.65 trillion industry, placing the power of physicians in direct relationship to the profitability of their services.[24] Some scholarship has claimed that in the United States, medicine is dominated by a biomedical philosophy that sees the body as a machine and illness as a dysfunction within that machine.[25] However, scholars such as Maya Dusenbery, Nicholas B. King, and Elinor Cleghorn have turned their attention to patterns in medicine representative of broader cultural issues, such as gendered discrimination in medicine, through which the medical humanities support further investigation.

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[22] Loretta Ross & Rickie Solinger, *Reproductive Justice: An Introduction*, (Oakland, California: University of California Press, 2017), 72.

[23] Virginia Aita, et al., "Patient-Centered Care and Communication in Primary Care Practice: What Is Involved?" (*Patient Education and Counseling*, vol. 58, no. 3, 2005), 297.

[24] Erik Sherman, "U.S. Health Care Costs Skyrocketed to $3.65 Trillion in 2018," (*Fortune*. Fortune, February 21, 2019), https://fortune.com/2019/02/21/us-health-care-costs-2/.

[25] Aita, "Patient-Centered Care and Communication in Primary Care Practice," 302.

In *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and* Sick, Maya Dusenbery examines the influence of gender bias in medicine. Dusenbery identifies how, "women are not taken as seriously as their male counterparts when they enter the medical system," and that, "Women face long delays, often years long, to get diagnosed even with diseases that are quite common in women."[26] Dusenbery's work shows that there are many diseases and health issues in which women face long delays to diagnosis. Since women are not taken as seriously as men in medical encounters, they are facing disparities in accessing timely diagnosis, which can be further explored through case studies of specific diseases, such as endometriosis. Contending with patterns of health disparities that predominantly impact women and people with internal reproductive anatomy, Dusenbery explains that "Advocates say individual patients can also create some bottom-up pressure for change by becoming informed themselves and bringing up these issues with their own doctors,"[27] adding that the pressure for women to self-educate and then advocate with their doctor is an unacceptable burden to the ill patient. Examining the limits of medical approaches designed in a "male model" system, Dusenbery critiques gendered medicine, in which:

> Women's symptoms are not taken seriously because medicine doesn't know as much about their bodies and health problems. And medicine doesn't know as much about their bodies and health problems because it doesn't take their symptoms seriously.[28]

Here, Dusenbery uses chiasmus, a rhetorical device in which the concepts are repeated in reverse order to emphasize the point. Dusenbery captures the vicious cycle in motion, wherein women's symptoms are reciprocally misunderstood and not taken seriously. The lack of medical research designed for people with internal reproductive anatomy, coupled with the tendency to dismiss

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[26] Maya Dusenbery, *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*, (New York: Harper One, 2018), 4.
[27] Dusenbery, *Doing Harm*, 58.
[28] Dusenbery, *Doing Harm,* 12.

women's symptoms results in broader patterns of misdiagnosis and medical gaslighting, in which doctors blame patients as making up their health issues. The historical approaches to medical research have left women out of clinical trials and particularly excluded pregnant women, which have led to a field of medicine designed specifically to treat men and people with external reproductive anatomy. My work builds on the reports of delayed diagnosis that Dusenbery identifies in *Doing Harm*, to deepen claims about *why* delayed diagnosis occurs and *how* the gender identity of women influences experiences for people living with endometriosis.

Other scholars have paid careful attention to the need to focus on justice-oriented conceptions of medical research. In *Understanding Health Inequalities and Justice*, Nicholas B. King contributes a chapter titled "Justice, Evidence, and Interdisciplinary Health Inequalities Research," in which he suggests the importance of seeing epistemology, scientific methodology, and normative judgement as conceptually and disciplinarily intertwined.[29] To adequately address health inequalities and social justice, these domains must be considered closely to make knowledgeable scientific claims, sound theoretical suggestions, and educated policy choices. King argues that empirical researchers often exaggerate their findings' significance, make unwarranted causal claims, and offer unjustified policy recommendations.[30] King suggests that to better address health inequalities and justice-minded medical research, we must be cognizant of what data do not show. My work responds to King's recommendations, reading the margins by centering the voices of those people with endometriosis who have historically been silenced in the process of developing a medical epistemology of endometriosis.

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[29] Nicholas B. King, "Justice, Evidence, and Interdisciplinary Health Inequalities Research," in *Understanding Health Inequalities and Justice: New Conversations Across the Disciplines*, (University of North Carolina Press, 2016), 214.

[30] King, "Justice, Evidence, and Interdisciplinary Health Inequalities Research," 228.

Some researchers have begun the work of evaluating women's experiences of illness through a historical account, such as Elinor Cleghorn in *Unwell Women: Misdiagnosis and Myth in a Man-Made World.* In a discussion about how cultural and social pressures have left women feeling shame about their bodies, Cleghorn argues that being unwell has been normalized. Cleghorn examines trends of gendered medical encounters from ancient Greece to the present in an account that argues that the history of medicine is social, cultural, and scientifically formed. Concluding, Cleghorn writes, "Our mysterious diseases are acknowledged as difficult to diagnose, manage, and treat. But the truth about our illnesses is in our own bodies. Medicine has to let us translate the languages they are trying to speak."[31] As this dissertation will explore, endometriosis provides a case study of a disease that is often difficult to diagnose for those afflicted, challenging to manage, and hard to treat. Endometriosis symptoms may cause pain, fertility challenges, or debilitation to signal to the afflicted body that there is abnormal tissue growing beneath the surface. Yet when folks report these symptoms, medical practitioners tend to silence such claims. To allow us to translate the languages that bodies with endo are trying to speak, reported symptoms warrant attention including the use of medical tests and labs to investigate the presence of abnormalities that the symptoms are signaling. Furthermore, endometriosis represents a necessary shift towards a medical structure that validates patient claims without requiring medical professionals to first confirm a diagnosis. Cleghorn explicitly states that the truth of our illness is found within our bodies and that shifting medicine towards a model that allows for people with illness to speak those truths is important. My work is a response to this call for approaching truths about our diseases through a case study of endometriosis, in which speaking to people with firsthand experience will allow people with

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[31] Elinor Cleghorn, *Unwell Women: Misdiagnosis and Myth in a Man-Made World*, (New York: Dutton, Penguin Random House LLC, 2021), 320.

endometriosis to share their bodily understanding to further what we know about the disease and delayed diagnosis. This dissertation centers endometriosis as a case study to further the work of authors like Dusenbery, King, and Cleghorn to provide a close reading of the tensions and ideological impacts at play for people living with endometriosis.

Gendered Dismissal of Women's Ailments: Hysteria and Endometriosis

The historical use of hysteria as a blanket diagnosis for women's symptoms represents how sick women have been conceptualized as both unreliable and responsible for their suffering. Scholarship has examined the patterns of a widespread distrust of women's reports of illness represented by Western medicine's historical tendency, "to throw many of women's inexplicable symptoms into the catchall diagnostic category of hysteria."[32] Hysteria represents a dismissive approach to diagnosing women with hard to understand illnesses, lumping many symptoms into a broad category that places undue weight on the role of the womb in a women's suffering.[33] The etymology of the term hysteria originates from the Greek word for uterus, hystera.[34] The emergence of hysteria in relationship to the uterus demonstrates an early gendered conceptualization of illness as connected with biological sex. Although women are not diagnosed with hysteria today, the legacy of the diagnosis remains, and women are often recommended to seek psychological treatment for physical ailments.

Endometriosis presents a unique cultural problem with a deep seeded history in the hystericization of women.[35] Although hysteria has been used widely to diagnose many diseases over time, recent work has indicated that perhaps many women living with endometriosis were

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[32] Dusenbery, *Doing Harm,* 11.
[33] Cleghorn, *Unwell Women*, 66.
[34] Dusenbery, *Doing Harm,* 63.
[35] Michel Foucault, *The History of Sexuality*, (New York: Vintage, 1990), 110.

misdiagnosed with hysteria.[36] Regarded as "one of the most colossal misdiagnoses in human history," research suggests that endometriosis has been misdiagnosed as hysteria in millions of cases.[37] Thus, millions of people, culturally gendered as women, struggling with the ravages of a painful and inexplicable disease that caused debilitating symptoms have been written off as having an illness best attributed as exaggerated or neurological. Presently, the discourse of hysteria is reflected in accounts of endometriosis delayed diagnosis because when patients report their symptoms, they are often similarly mistreated by doctors who tell them that they must be exaggerating or making up their symptoms. Consequently, beyond the significance of how many people were afflicted with the misdiagnosis of hysteria over the years, the gendered history of the overdiagnosis of hysteria informs trends in the diagnostic processes of endometriosis today. Therefore, endometriosis provides a case study of how gendered ideology has shaped medical encounters for people with internal reproductive anatomy on a mass scale that warrants further investigation.

Assumptions that a complaining woman is hysterical or that pain exists "all in her head" are a common misogynistic narrative that has been used against menstruators to denigrate their lived experiences associated with cyclical bleeding, pain, and discomfort.[38] Women in genuine pain have been dismissed by patriarchal society as hysterical:

> Just like hysteria was applied as a diagnosis to anything the physician didn't understand, today when women and others with female reproductive systems present with illnesses that defy current understandings of the body, they're diagnosed with medically unexplained symptoms, depression, other mental illnesses, or simply disbelieved.[39]

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[36] C. Nezhat, F. Nezhat, and C. Nezhat, "Endometriosis: ancient disease, ancient treatments," (*Journal of Fertility and Sterility*, 2012), doi: 10.1016/j.fertnstert.2012.08.001; Seckin, *The Doctor Will See You Now*, 20.

[37] Nezhat et al., "Endometriosis: ancient disease, ancient treatments," doi: 10.1016/j.fertnstert.2012.08.001.

[38] Jane M. Ussher, *The Madness of Women: Myth and Experience*, (New York: Routledge, 2011), 172.

[39] Gabrielle Jackson, *Pain and Prejudice: A Call to Arms for Women and Their Bodies*, (Great Britain: Piatkus, 2019), 114.

Many people who menstruate fear gaining a reputation as someone who exaggerates or who is mentally unwell if they report their health concerns related to menstruation. Unfortunately, the history of ascribing hysteria as a widespread diagnosis informs the patterns in which, "Women with endo often underplay the severity of their symptoms, because they think people won't believe them. But the pain is often more severe than most of us can imagine."[40] Thus, the historical attribution of hysteria to ill women has evolved into cultural understandings that women's pain is "all in her head," which continue the trends in which women suffering from endometriosis struggle to be diagnosed.

Historical Contextualization of Endometriosis: Myth of the "Career Woman's Disease"

There is a deeply interwoven connection between endometriosis diagnosis and treatment that also inform ideologies about who is accepted as a "woman" based on one's choice to, or not to, get pregnant. In the 1970s-1980s, endometriosis was coined the "career woman's disease" because it was believed to occur in women, "who have pursued careers at the expense of performing the more traditional roles of childbearing and housekeeping."[41] Thus, the profile of persons likely to live with endometriosis were those who put off pregnancy or perhaps opted out of it altogether in pursuit of a professional career. The false narratives about the "career woman's disease" portrayed people with endometriosis as working, middle class White women, excluding Black, Indigenous and people of color, gender non-conforming or trans folks, and unemployed people from the possibility of endometriosis diagnosis. Additionally, women who were raising children at home were not interpreted as likely to have endometriosis from a medical perspective. The early misconceptions about who might have endometriosis continues to misguide medical practitioners and patients seeking answers.

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[40] Cook, *Stop Endometriosis and Pelvic Pain*, 35.

[41] Seear, *The Makings of a Modern Epidemic*, 90

Recommended treatments for those diagnosed with the “career women’s disease” were similarly cultural in nature, with medical practitioners recommending their patients with endometriosis try, “childbirth, childrearing, breastfeeding, and the role of housewife.”[42] The prescription to return home to raise children was a culturally informed medical remedy, misguided by ideas that a woman pursuing a career over motherhood was responsible for her illness. The early conceptualization of endometriosis relied on cultural assumptions about gender roles that reinforced ideas that a woman’s place was in the home raising children. Doctors, perceived as experts, were making recommendations persuaded by cultural biases instead of scientifically tested treatments. The suggestion for people with endometriosis to stay home and have babies to heal from their illness presumed that careerism was causing their symptoms. In summary, the cultural messaging behind naming endometriosis the “career woman’s disease” insinuated that a woman with ambitions beyond motherhood, such as the active pursuit of a career, would cause them to become sick and their only way to recover required returning to their gendered role at home doing domestic labor.

Further complicating the historical conceptualization of endometriosis as the “career woman’s disease” is the brief suppression of endometriosis symptoms experienced during pregnancy. Many people with endometriosis experience relief from their symptoms while pregnant and breastfeeding. However, Dr. Cook suggests that the idea that pregnancy cures endometriosis is a myth. Instead, “Most women will find that any beneficial effects of pregnancy on endo are temporary, and they will experience a recurrence when their menstrual periods resume.”[43] Although there is subtle relief from endo symptoms during pregnancy, the prescription to give up on one’s career and return to domesticity is based on gendered

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[42] Seear, *The Makings of a Modern Epidemic*, 107.
[43] Cook, *Stop Endometriosis and Pelvic Pain*, 41.

assumptions of a woman's place in the home. Untangling the historical conception of who is likely to be diagnosed with endometriosis illuminates some of the current trends in endometriosis delayed diagnosis, in which certain populations are not as likely to be diagnosed with endometriosis. Uniquely, endometriosis is a disease with a history of doctors prescribing a life-altering decision that the disease itself might limit—pregnancy.

The early construction of who is likely to have endometriosis has led to assumptions that Black women are less likely to experience the illness. When endometriosis started to be diagnosed as the "career woman's disease," the message being sent was that only ambitious middle-class White woman who put off childbearing in pursuit of a career could develop endometriosis. In *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty*, Dorothy Roberts says that doctors' diagnosis of the cause for fertility challenges depends on race. Specifically, endometriosis, which can cause fertility challenges, has been regarded as the "career woman's disease" because "many gynecologists insist on associating endometriosis with a middle-class, professional lifestyle."[44] There is no epidemiological proof that career women are at an increased risk for endo. Many people living with endo are victim blamed by doctors through assessments that their stress of working life is driving their symptoms or fertility challenges, rather than the underlying endo. The misnomer "career woman's disease" has a dual effect that both stigmatizes White women's careerism as causing fertility challenges and it excludes Black women, who are less likely to be professionals, from the class of women whose fertility is treatable.[45] This leads to misdiagnosis of endo in Black patients and creates

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[44] Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty*, (New York: Vintage Books, [1997] 2017), 255.

[45] Roberts, *Killing the Black Body*, 256.

assumptions that harm Black women's health outcomes, causing additional barriers for people with endo who do not resemble the "career woman" of its early conception.

In, "Behind the Times: Revisiting Endometriosis and Race," Olga Bougie compares the early theories about endometriosis and race to those of cancer during the same period, "In the 1920s and 1930s, cancer, like endometriosis, was widely considered to be a disease of civilization, most common among White women who were susceptible to the stresses of modern life."[46] The media depictions of endo as a middle-class career woman's disease continued to persist into the 2000s even though, "(1) endometriosis can occur in women of any race and (2) women of various ethnicities may have different presenting symptoms of endometriosis and express different treatment preferences."[47] We know that endo does not only occur in White middle class women, but Black people are 50 percent less likely to receive an endometriosis diagnosis than White folks.[48] Thus, the myth of the "career women's disease" highlights the importance of tracing the cultural factors contributing to the delayed diagnosis of endometriosis to identify how the early ideas about endometriosis impact endo care today.

From emergent discussions of the mistreatment of women through medical humanities projects about the current trends of dismissal of women's symptoms to the historical use of the blanket diagnosis of hysteria in women, endometriosis provides a case study of how historical trends in medicine are produced through dominant gendered ideology. Further, the faulty diagnosis of women's careerism as a disease-causing life decision situates the importance of investigating endometriosis delayed diagnosis using methods alternative to traditional medical

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[46] Olga Bougie, Jenna Healey, and Sukhbir S. Singh, "Behind the Times: Revisiting Endometriosis and Race," (*American Journal of Obstetrics and Gynecology* 221, no. 1, 2019), 35.
[47] Bougie et al., "Behind the Times," 37.
[48] "ENDO Black, Inc.," ENDO Black, Inc., accessed May 8, 2021, https://www.endoblack.org/.

research. Aside from the mentions of endometriosis within broader discussions of reproductive health, rights, or justice discourses and the scientific publications about endometriosis centering clinical, laboratorial, or epidemiological studies in medical journals, endometriosis literature is limited in scope. Currently, there are few primary texts specifically about endometriosis. Limited publications are written for an audience that includes people living with endometriosis, loved ones of those with endo, or scholars interested in endometriosis as a political issue. Although limited, this dissertation draws on the work started by endometriosis specialists, Dr. Cook and Dr. Seckin, as well as Kate Seear, a sociologist, all of whom have written works intended for more generalized audiences than traditional medical literature.

Dr. Andrew S. Cook published *Stop Endometriosis and Pelvic Pain: What Every Woman and Her Doctor Need to Know* in 2012 to provide people facing endometriosis with information about the disease and guidance for improving their health. Cook's work begins by engaging in discussions about the reality of living with endometriosis to provide an overview of the disease and reject many of the myths associated with endometriosis. Then, Cook shares advice about getting a diagnosis and treatment for endometriosis. Cook's work offers a broad overview of endometriosis and how to navigate diagnosis and treatment but does not closely examine how cultural ideologies have influenced the ways in which endometriosis patients have been produced or interpreted.

Similarly, Dr. Tamer Seckin published *The Doctor Will See You Now: Recognizing and Treating Endometriosis* in 2016 to provide patients and their loved ones with an overview of the most important information related to endometriosis. Throughout his work, Seckin discusses the disease, symptoms, misdiagnoses, effects, alternative care treatments, the care you deserve, and support resources to provide readers with an overview of the disease. Dr. Seckin argues that for folks living with endometriosis, “Early detection and timely intervention are vital to the prevention of pain, suffering, and infertility.”[49] Seckin’s work is primary in helping readers to gain a deeper understanding of endometriosis in an accessible tone written for non-specialist audiences. Seckin’s work is an incredible resource of information for people looking to learn from a practicing specialist about endometriosis. However, like Cook’s project, Seckin’s work is grounded in the medical perspective of a practicing surgeon, elaborated through observational records from his work treating patients for years. Like Cook’s work, Seckin’s text provides meaningful information about the disease without deeply engaging questions related to why there remains a delayed diagnosis of endometriosis in the United States.

In the 2014 publication *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*, Kate Seear is the first to address endometriosis through a sociological lens to explore how endometriosis presents a case study of the social and political construction of ill subjects. Seear focuses on, “how the disease is articulated, lived, negotiated, materialized and performed,” using an experimental qualitative approach called pinboard pastiche.[50] The pinboard pastiche provides a framework through which Seear focuses on various avenues of endometriosis research without hierarchizing the materials, instead imagining that the lines of inquiry fall on a pinboard and exist alongside one another. In closing, Seear encourages future research to evaluate questions by centering women’s voices. Seear calls for future research to engage with questions such as, “How do women experience medical diagnosis, care and treatment? What new versions of self/body/agency are performed therein? Where are there inconsistencies and tensions in medical knowledge and practice, and how are they managed?”[51] Although this dissertation is

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[49] Seckin, *The Doctor Will See You Now*, 229.
[50] Seear, *The Makings of a Modern Epidemic,* 22.
[51] Seear, *The Makings of a Modern Epidemic,* 173.

unable to answer each of these questions in depth, my project does begin to address Seear's questions and build on the existing literature through my case study of people living with endometriosis.

This dissertation expands on how the historical and cultural conceptualization of endometriosis might inform present trends in the experiences of people with endometriosis. Although the ten-year delay in diagnosis of endometriosis in the United States has been widely reported, there has not been a study examining what cultural factors and biases are influencing the patient-doctor dynamic. As I will elaborate in the following section, this dissertation will use a qualitative research approach grounded in interviews with people living with endometriosis and autoethnography to develop what we know about the delayed diagnosis of endometriosis through research that positions people with endo as experts.

Methodology: Interviews and Autoethnography

The design of this study was centered around speaking with people living with endometriosis to highlight their voices and offer an opportunity for them to contribute to what we know about the disease. To prepare the data collection for this dissertation, I submitted a protocol to Claremont Graduate University's Institutional Review Board (IRB). I received verification of exemption approved without renewal from the IRB on April 28, 2021 to conduct this research. The criteria for people to participate in this study is that they have been medically diagnosed with endometriosis, are eighteen years of age or older, and reside in the United States. To complete my dataset, I recruited participants through snowball sampling using Instagram posts requesting interested parties sign-up by completing a Google Form to provide me with their email address. Once I posted the invitation to participate on Instagram, other friends and colleagues promoted my post through their Instagram stories to help encourage more people to sign up. The Instagram posts outlined my interest in conducting this research to encourage people with endometriosis to share their experience to improve the scholarship we have about the disease. Once participants shared their interest, I sent them a consent form to sign and return before moving forward with scheduling an interview. Once I received the signed Consent Form, I scheduled a one-hour Zoom interview and sent them a link to an optional demographic pre-interview survey.[52]

I conducted eighteen interviews with people living with endometriosis through Zoom. At the beginning of each interview, I read an opening script, in which I reiterated the participatory nature of the interviews and explained that each question was optional and that participants could discontinue participation at any time. The interviews were semi-structured, in which I asked a series of scripted open-ended questions[53] to maintain consistency across interviews. Each interview was recorded and saved to an external hard drive that only I have access to. Once interviews were conducted, I transcribed the interviews and assigned each participant a pseudonym to protect their privacy.

Each of the eighteen participants from the sample volunteered their time by completing a Google form to submit their interest in participating in the study. Of thirty respondents, eighteen people who signed up followed through by signing and returning a consent form, then showed up for a Zoom interview. The participants in my sample live all over the United States as depicted in Figure 1: Participant Location

Created with Datawrapper

Figure 1: Participant Location

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[52] See Appendix A: Pre-Interview Survey Questions for a complete list of survey questions.
[53] See Appendix B: Interview Questions for a complete list of interview questions.

Figure 2Figure 1, representing perspectives from different regions across the country. The participants all identified as cisgender women. Four ethnicities were represented across the sample, as represented in Figure 2, including White, African American, Native American, and Latinx or Hispanic, and five participants identified with multiple ethnicities. In total, 66.7 percent of participants identified as White, 38.9 percent of participants identified as African-American, 22.2 percent of participants identified as Latinx or Hispanic, and 11.1 percent of participants identified as Native American. The sample is limited in diversity but does capture some variance across diverse ethnicities.

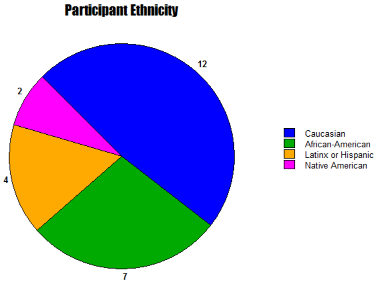
Participant Ethnicity

Figure 4: Participant Ethnicity

The sample demonstrates a broad range of ages. The sample participants ages ranged from twenty-three to forty-five years old, with a mean age of thirty-three-years-old. Of the fourteen people who responded to the question of when their endometriosis symptoms began, the average age at the onset of symptoms reported was seventeen years old, with participants sharing that their symptoms began as early as age ten or as late as age forty-two. Of the fourteen participants who responded to the question of what age they were when diagnosed with endometriosis, the average age reported was twenty-seven years old. The average time it took to receive a diagnosis for endometriosis across my sample was eleven- and one-half years, about a year and a half higher than the national average.

Participants symptoms varied across the sample. As demonstrated in Table 1: Participant Symptoms, the symptoms ranged and were reported with varying consistency.

Table 1: Participant Symptoms

Symptom	Frequency in Sample (% of sample)
Abnormal periods	13 (72.2%)
Menorrhagia (periods with heavy bleeding)	15 (83.3%)
Prolonged periods (7+ days)	7 (38.9%)
Dysmenorrhea (painful menstrual cramps)	17 (94.4%)
Lower abdominal pain	17 (94.4%)
Pelvic pain	15 (83.3%)
Lower back pain	15 (83.3%)
Dyspareunia (painful intercourse)	13 (72.2%)
Diarrhea	12 (66.7%)
Constipation	12 (66.7%)
Painful bowel movements	12 (66.7%)
Painful urination	6 (33.3%)
Frequent urge to urinate	10 (55.6%)
Nausea	14 (77.8%)
Vomiting	9 (50%)
Bloating/Endo belly	17 (94.4%)
Gassiness	10 (55.6%)
Nerve pain in legs	9 (50%)
Fatigue	17 (94.4%)
Personality changes	10 (55.6%)
Shoulder pain	8 (44.4%)
Infertility	10 (55.6%)

I used a snowball sampling method to recruit participants through Instagram, so the diversity of participants was limited. While a broad age range is included in the sample, future iterations of this project might target both younger and older demographics of those afflicted with endometriosis. For example, it would be useful to speak with post-menopausal people with endometriosis about how their experiences compare before and after menopause. Further, closer attention could be paid to class, educational background, or comorbidities to see if any of those factors emerge in relationship to the experience of delayed diagnosis of endometriosis.

In addition to conducting interviews with people living with endometriosis, this dissertation incorporates autoethnography as a methodological approach to include my firsthand experiences with endometriosis. It took me eleven years to be diagnosed with endometriosis, so I participate in this research both as the researcher and a participant in the production of medical knowledge about endometriosis grounded in firsthand accounts of patients. In each chapter, I open with a few pages contextualizing the themes of the chapter through my personal accounts as someone living with endometriosis. Then, in chapter four, I spend the entire chapter discussing my firsthand experiences with endometriosis delayed diagnosis and treatment. The autoethnography is written from my memories and represents my experiences as accurately as possible.

As an educated twenty-eight-year-old White cisgender straight woman who comes from a middle-class family in New England, my positionality shapes my unique experiences with endometriosis. I am not representative of the broader sample of participants who shared their time in Zoom interviews, and I believe the opportunity to speak with other people living with endometriosis enhanced this work because my experiences represent the privileges of my positionality. Unlike some of the other participants, I was heard in my early twenties by my primary care doctor and referred to a reproductive surgeon to receive a laparoscopic surgery to diagnose endometriosis. While my first surgery did not lead me to relief, being diagnosed in my early twenties is important since many people with endometriosis do not get diagnosed until the disease has spread to many organs, potentially causing permanent damage. The use of autoethnography further corroborates the themes that emerged from the interview dataset and contributes to my overarching approach to the research, in which I center people with endometriosis as medical experts on the illness. Thus, my role as the researcher is complemented by my position as someone diagnosed with endometriosis.

Chapter Outlines

Chapter One: Menstrual Ideology and Endometriosis Delayed Diagnosis

In chapter one, I highlight endometriosis as a case study of gender bias in medicine by analyzing how cultural ideology shapes healthcare interactions. I examine how cultural ideologies regarding menstruation have perpetuated gendered myths that menstrual pain is normal through examples of how menstrual pain has been indicated as "all in their head" in interactions between my interviewees and their doctors. I analyze themes that emerged in my interviews with people with endometriosis to discuss the impact of gendered ideology on their experiences and the consequences of presenting menstruation as culturally taboo for folks seeking an endometriosis diagnosis. Throughout chapter one, I argue that myths that menstrual pain is normal may contribute to the ten-year delay in diagnosis of endometriosis.

Chapter Two: "Performing Wellness" and the Rhetoric of Endometriosis Self-Help Literature

In chapter two, I combine a critique of the endometriosis self-help genre and an analysis of how people with endometriosis adopt strategies to publicly censor their experiences to avoid negative attention regarding their illness. The threads of analysis engage a discussion of how endometriosis represents the neoliberal tendency to victim-blame, in which ill persons are tasked with their own recovery. In chapter two, I argue that the cultural expectations reified and perpetuated through endometriosis self-help literature contribute to a rhetoric of individualistic healing that places the social responsibility to heal on those suffering. Moreover, in this chapter, I discuss cultural expectations for people who do not appear visibly ill to behave as though they are healthy for the comfort of others. The pressure for folks suffering with endometriosis to take responsibility for their illness leads many to adopt coping strategies to hide their suffering. In this chapter, I introduce the concept of *performing wellness*, a phenomenon I coin to explain the dissonance between ill persons' experiences with their symptoms and their presentation of behaviors of wellbeing. I interrogate how endometriosis patients hide their illness as a survival strategy to navigate United States cultural expectations and theorize what such pressure represents about United States healthcare. Finally, I engage with how the phenomenon of performing wellness is a response to the broader rhetorical messaging coalesced within endometriosis self-help texts, which are factors that may contribute to the delayed diagnosis of endometriosis.

Chapter Three: Advocating for Self: Towards Endometriosis Diagnosis & Epistemic Justice

In chapter three, I explore additional themes that emerged from the eighteen one-hour Zoom interviews with people living with endometriosis including how participants: 1) Emphasized the importance and uses of self-education in the process of endometriosis diagnosis; 2) Reported a process of self-advocacy serving in the process of endometriosis diagnosis; 3) Shared the mental health impacts of living with undiagnosed endometriosis that emerged from living with unexplained chronic physical symptoms of the disease; 4) Described a deep sense of validation once they finally received a diagnosis. As discussed in chapter one, the patterns of doctors dismissing patient accounts of menstrual pain is an epistemic injustice, in which doctors do not consider patient reports to be reliable. Throughout chapter three, I argue that people with endometriosis know their bodies well and are aware of their illness, often before they have a medical diagnosis. Thus, I situate my work as a manifestation of epistemic justice, through which the firsthand accounts of those living with endometriosis demonstrate their reliability as experts on their illness.

Chapter Four: Endometriosis: Reflections on Reclaiming My Health

A departure from the previous chapters, in chapter four, I write from an autoethnographic approach. My experience with a real-life issue that impacts 200 million people worldwide propelled my curiosity about how the prevalence of trends of the delayed diagnosis of endometriosis might be overdetermined by cultural ideological constraints. Throughout this dissertation, I position people with endometriosis as holding embodied knowledge of the disease and therefore the incorporation of a chapter centering my experiences as a member of the endometriosis community serves to corroborate the themes uncovered throughout the interviews. In this chapter, I share my history with menstrual-related symptoms and pursuit of endometriosis diagnosis and treatment to offer personal insights regarding the layered complexity of living with endometriosis.

Throughout this dissertation, I begin to untangle some of the complex cultural forces that contribute to the delayed diagnosis of people living with endometriosis. Beyond identifying some of the cultural factors shaping the medical encounters of those living with endometriosis, this work begins uncovering opportunities for improving the time to diagnosis for the one in ten people with internal reproductive anatomy living with endometriosis. This dissertation provides new methodological approaches to developing medical epistemology by placing value on patient accounts as significant in the process of medical knowledge production. Listening to the stories of people living with endometriosis, I attempt to demystify some of the cultural constructions of endometriosis that are grounded in biased imaginations of ideal womanhood to document more firsthand representations of what it means to live with endometriosis. This dissertation explores how gender shapes the medical experiences of many people living with endo to critique the medical sexism in the United States medical industry. Finally, I hope that this dissertation helps medical practitioners, employers of those living with endometriosis, loved ones of those living with endometriosis, and the 200 million people living with endometriosis to understand the disease differently- not merely as an illness in need of cure, but as a representation of unresolved cultural influences of misogyny in need of dismantling. I hope this work contributes to ongoing discussions of reproductive rights and justice, and positions endometriosis as a case study of the broader impact that medical sexism has on the lives of those victimized by its oppressive forces.

Chapter 1: Menstrual Ideology and Endometriosis Delayed Diagnosis

Countless pelvic exams
Always lead me
To gulping down gasps
While my knuckles
Turn so white they
Bleed straight into
The crinkling paper
Plastered under my thighs.
Gloved fingers lead to
Trying to catch tears
In my eyelashes,
To halt hysteria
Lest this doctor, too,
Blame pelvic pain
On the brain.

-Pelvic pain shouldn't be normalized.[54]

Doctors had always reassured me that pain with menstruation is typical, so I should not be too concerned. I could just, "regulate with birth control." At least that is what my primary care and subsequent gynecologists suggested when I would report abnormally long periods with severe premenstrual syndrome and frequent pain.

While my first sign of endo was prolonged and heavy menstruation, the older I got, the harsher the cramps and back pain associated with my period became. Before my first surgery, I was nauseated from the severity of my cramps. The throbbing, burning, and nightmarish feeling that someone was scraping my insides became unmanageable. I would gasp, groan, and whimper through my long shifts serving at the local diner. My lower back pain was so severe that sitting, standing, and stretching all caused me to quiver. I squirmed around, trying to find a position that would offer some relief. My cramps were difficult to wait through, while my lower abdominals

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[54] Maggie Bowyer, *When I Bleed: Poems about Endometriosis*, (Greensboro, North Carolina: Margaret Bowyer, 2021), 59.

felt like my insides were locking up. I was readily stocked with ibuprofen and heating pads everywhere I went. Some days, my stomach would bloat in an exaggerated way that made me look pregnant. Many days it felt like there was a balloon in my abdomen filling and pushing on my organs, like it was ready to burst. The sensation that someone was carving my insides and scraping them with a chisel punctuated long days of fatigue, nausea, spotting, bleeding, or painful cramps. When those who loved me asked how I was doing, I told them that I wish I could merely crawl out of my skin.

It felt like my body betrayed me, that somehow, I deserved this suffering. Sometimes I wondered if I was feeling pain related to menstruation because of how long I listened to patriarchal ideas about womanhood. I wondered if I had internalized self-hate because of the inferiority I felt in a family divided by distinct gender roles. I wondered if internalized hate could substantiate the symptoms I suffered. The doctors said I was fine, so maybe it was just in my head? That could not be right— I could not believe that the pain I experienced was "normal."

Having recovered from a successful deep excision surgery, today I am cautious to report that I live mostly symptom-free. I now realize how detrimental the years of suffering were, how severe the pain truly was, and I am in awe that I continued functioning as I had, while facing such nasty symptoms from endometriosis. I also live with fear that the endo will return, as it does for so many.

Although my journey has led me to relief, I had one unsuccessful surgery before I started to educate myself about endo. When I discovered more endo warriors through Instagram, I started to realize that my experience was not unique. It became apparent that I was not the first person to face doctors who said that menstrual-related pain is nothing to get too worried about. Once I started to read more and realized that I am part of the one in ten people with internal reproductive anatomy living with endo, I became obsessed. Why are these patients' reports of pain silenced? How could there be such a widespread miseducation of menstrual pain as "normal," and for what purpose? My story is not rare, and I am determined to underscore the voices of others who have fought to receive a diagnosis for their endometriosis to initiate a deeper conversation about how doctors with gender bias are, though perhaps unintentionally, causing harm to the people they have sworn to treat. There are an estimated 200 million people living with diagnosed endometriosis, and with the average ten-year delay to diagnosis, there are many more living with undiagnosed endo.[55] The numbers are stark and this chapter is an attempt to give voice to those who have or continue to suffer due to their diagnosis.

In this chapter, I ask questions like, how does the myth of gender, that is, the contradictory expectations ascribed to women, shape cultural conceptions of pain? Women face conflicting expectations, such as the cultural responsibility to endure childbirth, which is widely accepted as one of life's most painful experiences. Then, women are evidently held to a double standard because when they share symptoms of pain, they are often dismissed as exaggerating or told that their pain is normal, which conflate what it means for women to experience pain. Tracing the link between womanhood and pain, I further question how the normalization of menstrual pain might affect the delayed diagnosis of endometriosis. First, I discuss how gender bias in medicine is an example of epistemic injustice and engage with how centering endo patients' voices can combat such injustices. Then, I discuss how the cultural concept of gender creates myths about bodies related to reproduction. I connect how gendered misconceptions ascribed to women's bodies are implicit in cases of endometriosis delayed diagnosis.

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[55] Dan Martin, "Endometriosis: Defining It, Recognizing It, and Treating It," (Endometriosis: Causes - Symptoms - Diagnosis - and Treatment. Endometriosis Foundation of America, September 28, 2022), https://www.endofound.org/endometriosis.

This chapter is derived from eighteen interviews conducted with people living with endometriosis. Each interview was conducted through Zoom and recorded so that I could transcribe the material later. Each interviewee was asked the same series of questions.[56] After transcribing the interviews, I reviewed them to identify recurring themes, through which the focus of this chapter emerged. In the following, I share examples from my interviews with people living with endometriosis to expose how the myth of pain as a "normal" part of menstruation is implicit in the unnecessarily prolonged delay in diagnosis for people living with endo. To deduce further implications from my data set, I will share examples from my interviews of conversations that my participants had with me to support my interpretations of how patients have been conceptualized by their doctors, and further, I will attempt to analyze what some of the implications of those assumptions are. Namely, I share how my interviewees reveal the commonality of myths that menstrual pain is "normal" or the prevalence of doctors' dismissals of endometriosis symptoms as only in the patient's mind. This chapter is a response to Dr. Cook's call for refutations of dominant cultural myths about endo in which he states, "If women with chronic pelvic pain and endo start challenging the myths and archaic attitudes, they will eventually teach people, including healthcare specialists, about the realities of the disease."[57] Each of the participants in my study showed up for interviews because they similarly value the potential impact that sharing their experiences might have on the diagnostic delay of endo. They all wish to shift dominant narratives about endometriosis and menstrual pain to contribute more accurate depictions of endometriosis and to help disrupt the trends of misdiagnosis and delayed diagnosis. Finally, through an analysis of themes that emerged in my interviews with

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[56] See Appendix B: Interview Questions for a complete list of interview questions.
[57] Andrew S. Cook, *Stop Endometriosis and Pelvic Pain: What Every Woman and Her Doctor Need to Know*, (Los Gatos, California: Femsana Press, 2012), 123.

endometriosis patients, I discuss the impact of gendered ideology on real-life women and some of the consequences experienced by people seeking an endometriosis diagnosis.

I conducted interviews with folks diagnosed with endometriosis to center their firsthand accounts of living with endometriosis as valuable in the development of endometriosis research. To right the epistemic injustices of relying solely on medical practitioners as experts of medicine, I consider people with endometriosis authorities on their experience of the disease and how their interactions can expose why there remains such a long delay to diagnosis. Further, by listening intently to people living with endo's stories, I start to uncover the impact of the myth of menstrual pain as a normal part of life and the real-life repercussions it has on folks with undiagnosed reproductive disease. Centering the stories of people with endometriosis instead of prevailing scientific opinion is an attempt at epistemic justice in which patients are considered reliable sources to their diagnosis and healing journey. My work pushes back on hegemonic understandings of medical epistemology to provide an alternative strategy for learning about endometriosis delayed diagnosis through a qualitative approach. By listening to people with endometriosis talk about their interactions reporting their pain to doctors, friends, and family members, we start to recognize that the delayed diagnosis of endo has less to do with a lack of diagnostic capabilities and more to do with distrust and poor communication that influence how doctors perceive and respond to patients' reports of symptoms. In this study, gender bias in healthcare signifies a barrier to women and people living with endometriosis who are seeking diagnosis. The cultural myths surrounding menstruation and reproduction are implicit in doctor recommendations and diagnostic practices, leading many people with endometriosis down long roads to diagnosis and subsequent treatment. The most common and insidious pattern surfacing across my sample, is the tendency for young menstruators to be taught that painful menstruation is "normal."

The testimony of my interviews confirms that when a patient is told that their pain is "normal" they run the risk of internalizing pain as something to expect. Their perception of how much pain is tolerable becomes clouded because they start to believe that feeling pain is a typical part of life, rather than a signal of an underlying condition. Sophia, a 37-year-old participant from California explains the impact of being told that menstrual-pain is normal in the following way:

> I think that I had had so many times where like I was told, 'Oh, this is normal,' that I just saw the spectrum of quote unquote, 'normal female experiences,' maybe on a much wider range than what would be typically considered within normal limits, I'm guessing. So, I feel that I had such a skewed perspective on quote unquote, 'normal,' that I wouldn't even have known to discuss these things with the women that would have been like, 'That's not normal and you need to go talk to a doctor that listens.' So, I think I had been so taught …not like propaganda, but so brainwashed into thinking, 'Oh, this is normal,' that I didn't even realize to bring it up, I guess.

My research reveals how the dominant portrayal of menstrual pain as "normal" situates folks who are suffering with debilitating symptoms as unable to identify the need for medical intervention. The repeated messaging to Sophia that her symptoms related to reproductive and menstrual health were "normal" led her to develop a warped perspective of women's health, one in which pain is considered an expected part of womanhood. Over and again, she was told that her symptoms were "normal," so much so, that she felt "brainwashed" by her doctors, which caused her to dismiss the urge to share her experiences with anyone. I suggest that this is not merely a problem in medical diagnosis, but of gendered conceptualizations of health, medicine, and pain. The normalization of pain generates a sense that any pain associated with menstruation is to be expected. However, for people with endometriosis, pain can occur throughout the month and is often severe to the point of debilitation, which warrants medical investigation.

The long delay in diagnosis of endometriosis tends to represent a series of dismissals or misdiagnoses, regardless of the shared narrative amongst people with endometriosis that their menstruation is debilitating. Importantly, Carel and Kidd suggest in "Epistemic Injustice in Medicine and Healthcare" that, "Most ill persons are capable of describing their experiences in non-expert terms, but such experiences are often considered inappropriate for public discussion [and] are seen as private, if not shameful."[58] The taboo associated with menstruation— which refers to the conceptualization of menstruation as inappropriate for public discussion due to the stigma that it is a dirty, private, or shameful process— hints towards why doctors do not integrate patient accounts as valid in the process of diagnosis for menstrual-related illness. The dismissal of patient accounts by their doctors also implies that patient reports of menstrual pain are not useful in medical epistemology.

The gendered expectation for women to hide their experiences with menstruation sets the tone for common trends in medical practice that were discussed throughout my interviews with people living with endometriosis. Previous studies, such as Kate Seear's "The Etiquette, of Endometriosis: Stigmatization, Menstrual Concealment and the Diagnostic Delay," center around the lengthy delay to diagnosis of endometriosis and the significant impact it can have on women's lives. Seear responds to prior research that suggests that the role of women, their friends, families, and health professionals in the normalization of menstrual pain are a key factor in the diagnostic delay. Seear extends the argument by suggesting that "women seek to minimize the stigmatization associated with menstruation through strategic management of information

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[58] Havi Carel and Ian James Kidd, "Epistemic Injustice in Medicine and Healthcare," In *The Routledge Handbook of Epistemic Injustice*. (New York: Routledge, 2017), 341.

about their menstrual cycle, in the form of 'menstrual etiquette.'"[59] The learned approach of censoring discussions about menstruation is a factor embedded within the interviews I conducted with people with endo, many of which who shared that they were not always comfortable speaking about menstruation but became more vocal about it due to the severity of their symptoms. Pivoting towards open conversations around menstruation is necessary in destabilizing cultural gender "norms" and will improve developing research about endometriosis. The shame associated with menstruation must be eliminated to improve patient-doctor conversations about menstrual-related symptoms so that patients and their doctors can engage in open, honest discussions. However, as I will elaborate in the following, the reported dynamics between patients and doctors signify a site of epistemic injustice, wherein patients are not viewed as credible informants regarding their health experiences.

Epistemic Injustice in Medical Contexts

The interactions between patients and medical professionals constitute a unique relationship in which a patient invests their time and money into their doctor as an expert in teaching the patient about their condition. While it might be assumed that this is a collaborative interaction, in which a doctor listens and values the input of their patient in determining a diagnosis or treatment, in many cases doctors do not adequately weigh the input of their patients' reports. Due to knowledge asymmetries in medical contexts, epistemic norms dominate the knowledge considered credible, "…privileging the knowledge derived from medical training and theory, rather than that potentially rooted in patient experience, which effectively limits epistemic authority to healthcare practitioners."[60] The dichotomy in which doctors are seen as

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[59] Kate Seear, "The Etiquette of Endometriosis: Stigmatization, menstrual concealment and the diagnostic delay," (*Social Science & Medicine* 69, 2009), 1225.

[60] Carel and Kidd, "Epistemic Injustice in Medicine and Healthcare," 336.

experts of their patients' bodies represents potentially dangerous forms of epistemic injustice when it comes to patient-centered healthcare. Carel and Kidd suggest, "…asymmetries, dependencies, and power relations can increase the vulnerability of patients to epistemic injustice."[61] People fighting illness are already vulnerable due to the repercussions of undiagnosed pain and mental health challenges incurred due to the process of seeking treatment for their undiagnosed illness. People with undiagnosed endometriosis are often navigating both the challenge of managing their symptoms and their mental health when meeting dead ends in medical appointments.

Additionally, endometriosis provides a case study of "willful hermeneutical ignorance," an epistemic injustice in which dominantly positioned folks explicitly disregard the knowledge-making tools of marginalized folks.[62] When patients are not valued as participants in their health journeys and expertise is only attributed to medical doctors, there can be missed opportunities to identify root causes of symptoms. Marginalized folks do not have access to the same epistemic tools as those in positions of power because of their situatedness within the larger context of society. The reliance on knowledge production by and for dominantly positioned social actors, limits the emergence of epistemic contributions by marginalized knowers, resulting in the further marginalization of those folks. This phenomenon, known as epistemic oppression, is defined as, "… routine and harmful exclusions from some domain of knowledge production."[63] Epistemic oppression names the omission of marginalized peoples' knowledge, such as the knowledge a patient has of their own body and symptoms that is dismissed by their doctor. Like the standpoint epistemology of cultural studies and feminist critique grounded in identity, epistemic oppression

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[61] Carel and Kidd, "Epistemic Injustice in Medicine and Healthcare," 336.

[62] Gaile Pohlhaus Jr., "Relational Knowing and Epistemic Injustice: Toward a Theory of 'Willful Hermeneutical Ignorance,'" (*Hypatia* 27, no. 4 2012), 715.

[63] Kristie Dotson, "A Cautionary Tale: On Limiting Epistemic Oppression," (*Frontiers* Volume 33, no.1 2012), 36.

centers how the unique experience of an individual can serve as a contribution to knowledge production. While this dissertation draws from standpoint epistemology of people with endometriosis as knowers of their bodies and illness, epistemic oppression offers an additional layer for understanding how that knowledge has been (mis)interpreted and (in)validated within medical encounters.

Epistemic oppression provides a theoretical framework through which to examine sites of power differentials in knowledge production and epistemic injustice refers to examples in which knowledge produced by and for marginalized folks is invalidated or excluded. For example, conversations with interviewees in my case study show that knowledge produced by and for doctors is often validated, whereas knowledge produced by and for endometriosis patients is often dismissed and devalued by doctors in positions of authority. Doctors participate in epistemic violence through negating patient agency as producers of medical knowledge in general. More specifically, when patients report their menstrual-related pain and doctors do not consider their pain symptoms as valid, never mind significant or alarming, there is a devaluing of patient's knowledge. Instead, the doctor considers their expertise of reproductive health efficient in identifying that nothing is wrong with the patient. The cultural assumptions that menstrual pain can be expected blur the lines of medical response when patients report their period pain.

There remains a cultural value attributed to trained medical professionals at the expense of patient self-knowledge. In the case of gendered medical bias, we see the impact of how, as Pohlhaus Jr. describes, "…predominantly recognized epistemic resources are most likely to make better sense of that which arises from the experienced world of the dominantly situated than that which arises from the experienced world of the marginally situated."[64] Since hegemonic

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[64] Pohlhaus Jr., "Relational Knowing and Epistemic Injustice," 719.

epistemology is developed within the constraints of gendered thinking, the experiences of marginally situated women are not validated. Thus, resources to progress knowledge prioritize the hegemonic mainstream authority and often are not positioned to evaluate or develop new understandings about those situated marginally, such as the case of people living with endometriosis or other reproductive illness. Importantly, Alan Bleakley, a medical humanities scholar argues, "The historically conditioned authoritarian and hierarchical nature of medicine is also patriarchal and imitates oppressive post-colonial contexts."[65] There is a distinct power dynamic at play, especially when a cisgender man doctor is treating a cisgender woman or transgender man for illness that involves their reproductive organs. There is a sense of the doctor imposing their position of power as an outsider looking in at the uncharted territory of the "othered" body of the ill person. Using their authority in the situation, the doctor makes assumptions about their patient, imposing their beliefs onto the patient, echoing the imbalanced experiences of folks expected to assimilate to a dominant ideology that might not recognize or integrate them or their needs. Thus, traditional forms of medical education and practice rely on the prioritizing of expert knowledge, excluding from practice the possibility of patients contributing to the development of new knowledge, even though they have the firsthand experience with their given illness.

Medical Humanities Towards Epistemic Justice

Some medical humanities scholars such as Havi Carel, and Ian James Kidd suggest that there has been a shift towards valuing narratives in medical education, emphasizing the importance of listening to and considering patient-narratives to progress clinical practice.[66]

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[65] Alan Bleakley, *Medical Humanities and Medical Education: How the medical humanities can shape better doctors*, (New York: Routledge, 2015), 19.

[66] Carel and Kidd, "Epistemic Injustice in Medicine and Healthcare," 344.

Therefore, previously dismissed sites for knowledge production such as patients expressing themselves through narrative are starting to gain traction as legitimate forms of expression.[67] Further, Bleakley suggests that, “medical knowledge is narratively structured,” and supposedly, “doctors learn to diagnose and treat from repeated exposure to patients’ stories, thinking narratively.”[68] However, in the case of endometriosis, it seems like common patient narratives are repeatedly ignored, which results in dismissal or misdiagnosis.

In this dissertation, the voices of people living with endometriosis are integrated as authorities on the subject to combat historical medical epistemic injustices. Bringing a humanities approach to medical research has the potential to re-educate folks to value the power of sensibility and sensitivity as critical components of medicine that can politicize students, patients, and practitioners towards a democracy of medicine.[69] Democracy of medicine necessitates integrating patient accounts and narratives into medical epistemology. Thus, in the following, I explore the firsthand accounts of endometriosis patients to reconceptualize the historically gendered illness and begin to flatten the hierarchies of medical epistemology to instead value patient accounts as valid data for the advancement of medical research.

Gender, Medical Epistemology, and Endometriosis

Today, the interactions between a patient and the healthcare establishment emphasizes the gender roles that have been culturally ascribed to women. Patients from my sample discussed gendered implications in their healthcare encounters. The connection between the Western biomedical establishment and treatment of women came up throughout my conversations with endometriosis patients. Jade, a 42-year-old healthcare worker from California explained in detail:

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[67] Carel and Kidd, “Epistemic Injustice in Medicine and Healthcare,” 342.
[68] Bleakley, *Medical Humanities and Medical Education*, 18.
[69] Bleakley, *Medical Humanities and Medical Education*, 4.

> It's just kind of like opening Pandora's box. I think that our medical system is not garnered towards women's health. I think that for women, especially girls, to genuinely be taken seriously, there has to be a broken bone— some sort of evidence— that a doctor can say, ‘Okay, I can see this.’ It can't be anything that someone can blow off as a mind, you know, a mental sort of anxiety or imagined hysteria of some sort. I think that our medical system, and a lot of medical systems are really garnered towards men. And they just don’t, to say that the medical practice, that the treatment is not there, is a falsehood. The treatment is there, the research we have, we know how to treat. It’s medical professionals actually listening to their patients and giving good patient care, to get down to the very heart of it. And this is something that I, as a medical professional, this is something that for me is very much to heart. American medical is not garnered towards real patient care. We are garnered towards the almighty buck. And you see that in how much time doctors take with their patients. You see that with how much they actually listen. There have been a number of times where I've gone into a doctor's office, and the doctors were looking at my paperwork while they were talking to me. They did not know why I was there, what was going on, what my situation was, what my history was. They were trying to learn that, while they were trying to listen to me. And so, when you do that, you lose things, things that you just you can't, you cannot absorb that much information all at one time. And I think that when it comes down to it, it's all about patient care. And that's something that our, our medical system is really lacking.

In the first part of the above quote, Jade shares her concerns about the general gendered bias and tone of the United States medical establishment and its treatment of women patients. Noting that without visible evidence, women are not taken seriously for their symptoms, Jade critiques the limitations of a sexist medical establishment. Further, Jade shares how doctors often dismiss women by providing excuses that treatment is not available. In her account, Jade pivots quickly from a discussion of gender bias towards an observation that the design of the United States healthcare system is situated to focus on profit over patient outcomes. The close mention of these two characteristics starts to construct a profile of how the United States medical establishment currently operates.

In many instances, cultural ideologies impact patient interactions in the doctor’s office because a patient invests so much trust in the authority of a doctor as an expert. Historically the medical profession has been predominantly comprised of men, so there has been a power differential between endometriosis patients and their doctors. Notably, Maya Dusenbery reports in *Doing Harm* that the number of women working in obstetrics and gynecology increased from 12 percent in 1980 to just over 50 percent in 2018.[70] Although patients see doctors as experts, doctors do not often project the same confidence in their patient's ability to recognize and report their symptoms. As Catherine Swann argues in "Reading the Bleeding Body," largely practiced by men, medicine is partial, operating through "the gendered nature of their gaze," through which doctors practice medicine grounded in faulty assumptions that privilege the male body and devalue female patient experiences.[71] Since most medical practitioners have historically been men, the gendered nature of medical practitioner's gaze is that of the powerful authority, considered expert, even though they might not always have the ability to relate to the experiences of their patients. The gendered nature of the gaze operates by combining prevailing medical knowledge with gendered conceptions of medicine, which have been informed by sexist practices in medical education. Western medicine has been derived of a model in which there was an assumption that little differed between male and female bodies aside from size and reproductive role. Caroline Criado Perez says in *Invisible Women* that for years, "medical education has been focused on a male 'norm', with everything that falls outside that designated 'atypical' or even 'abnormal.'"[72] Beginning with medical educational training, gender is a factor crafting how medical practitioners understand and address their patients, a result of gender data gaps in medical textbooks and medical-school curriculum.[73]

The lines of sex and gender are often blurred in medical contexts, but the terms are not interchangeable. In the simplest of definitions, sex refers to categories that distinguish people by

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[70] Maya Dusenbery, *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick,* (New York: Harper One, 2018), 8.

[71] Catherine Swann, "Reading the Bleeding Body: Discourses of premenstrual syndrome," In *Body Talk: The Material and Discursive Regulation of Sexuality, Madness and Reproduction.* (London: Routledge, 1997), 180.

[72] Caroline Criado Perez, *Invisible Women: Data Bias in a World Designed for Men*, (New York: Abrams Press, 2019), 196.

[73] Perez, *Invisible Women*, 198.

the reproductive anatomy of their body, designating someone with external reproductive anatomy including a penis and testicles as male and someone with internal reproductive anatomy such as the vagina, cervix, uterus, and fallopian tubes as female. Gender refers to socially constructed norms regarding behaviors, roles, and expression of one's identity, derived from assumptions based on biological sex. I select to refer to people with internal or external reproductive anatomy to distinguish the sex organs one is born with to remove gendered assumptions from my presentation of people with endometriosis. I attempt to degender the conversation to focus on how the *presumed* gender ascribed to people because of their assigned sex influences their medical experiences. Since people with internal reproductive anatomy are assigned female at birth and are presumed to be women, they face specific social and cultural expectations that often trickle into medical encounters and impact how they are perceived.

Miseducated doctors can provide patients with internal reproductive anatomy with information that can lead them to feel at fault for their suffering, or perhaps that their symptoms are only in their mind because of presumptions that these patients are women. Although it might be undesirable, endo patients have often shown up for appointments with a doctor who has different reproductive anatomy to address concerns directly related to that difference. In their search for answers, endo patients have invested hope, desire, and money in doctors who do not represent them biologically. Importantly, sometimes doctors do represent their patients biologically, but due to their training within a medical system designed to address the health of people with external reproductive anatomy, gender biases continue to guide their approach to patient care. Therefore, it is possible for doctors to treat patients of the same sex ineffectively, just as well as it is possible for doctors to treat patients of the opposite sex effectively. In my sample, it becomes evident that relationships between doctors and patients, regardless of the doctor's reproductive anatomy, have been fraught with distrust, disbelief, and challenges communicating.

Gender shapes healthcare through the perceptions of bodies, providing further explanations for the misunderstandings of women's bodies. In *Doing Harm*, Maya Dusenbery identifies the two major gaps that contribute to the poor care for women in healthcare in the US today. First, there is a knowledge gap, such that, "…the average doctor does not know as much about women's bodies and the health problems that afflict them," and second, there is a trust gap, such that, "…women's accounts of their symptoms are too often not believed."[74] The two gaps combine to leave women misunderstood and misinterpreted in medical contexts. The lack of understanding and tendency to dismiss women's symptoms results in misdiagnosis or medical gaslighting in which doctors blame patients as making up their health issues.

The disbelief of women patients is perpetuated through repeated dismissals of menstrual pain as normal. Women are faced with cultural and behavioral expectations because of their gender identity. Since endometriosis is mostly found in people with internal reproductive anatomy, the disease is linked to gendered assumptions about women. Gender functions as a conceptual framework that informs how medical practitioners, friends, and family conceptualize women's health. The link between gendered ideology and women's health provides an entry point for the examination of how the experiences that my interviewees reported uncover cultural factors influencing the delayed diagnosis of endometriosis.

In the following, examples of how participants described their menstrual symptoms and interactions with doctors corroborate other trends in women's health research in which women are not taken seriously by their doctors. Starting with an analysis of prevailing myths grounded

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[74] Dusenbery, *Doing Harm*, 11.

in sexist patriarchal notions of womanhood, which construe menstrual pain as an expected part of life, I argue that the epidemic of endometriosis delayed diagnosis is a cultural phenomenon that can be consciously addressed. Additionally, I share examples of how symptoms have been dismissed as “all in their head,” complicating issues of gendered perceptions clouding endometriosis diagnosis. Finally, this chapter culminates in a discussion of the link between endometriosis and fertility to further examine the insidious consequences of gendered roles within reproductive healthcare.

Normalization of Menstrual Pain and Symptoms of Endometriosis

Throughout my interviews, participants described the pain they felt due to endometriosis as debilitating and unmanageable. Seventeen out of eighteen, or ninety-four percent of the participants reported experiencing pain associated with their endometriosis. One participant shared that they experienced, “…pain where I can’t do daily stuff,” and another simply stated that, “It [endometriosis] means pain.” Others defined endometriosis as, “a lot of pain,” “horrible,” “pain so bad I was nauseous,” or “pain so bad I was crawling on the floor.” Grace, a 30-year-old woman from Illinois, provided one of the most vivid descriptions of endometriosis pain, describing the pain associated with endo as follows:

> I always explain the pain as somebody took a pair of needle nose tweezers. Made them hot and are poking you from the inside out. Hot tweezers. Because it's pointy, it’s sharp. But I'm like what's pointy like that? Like, it's not really a needle because the needle is thinner. Like, no, it's like hot tweezers. Pinching and poking and twisting on your, yeah. But they're hot. Like burning.

Vivid descriptions of pain, such as the one from Grace above, demonstrate that the pain associated with endometriosis is not merely a “bad period.” Rather, it is a disturbing sensation that feels inescapable. The burning and pinching is sharp and pointed. The multitude of comments about pain shared by participants exemplifies the commonality of this symptom of endometriosis and the reality of pain with menstruation, despite doctors' dismissal.

Despite the severity of the pain related to endo and the participants' ability to describe their experiences, they often reported that they were not taken seriously by doctors. Throughout my conversations with participants, the folks I spoke to living with endo reported that their doctors consistently dismissed their reports of pain. Further, many of my participants shared that when they reported pain symptoms related to menstruation, their doctors told them that "this is normal," or that "changes [in menstrual patterns] are normal, pain is going to change," or "oh, that's normal," and that "doctors kept saying it's normal." The dismissal of pain as "normal" is a consistent pattern across my sample. Although endometriosis specialists know that pain is a clear indication of endometriosis, there appears to be a gap in medical awareness that pain with menstruation is a symptom, not a part of "womanhood"- which is, itself, a culturally produced stereotype mapped through gendered assumptions, not a scientific category. Doctors participate in perpetuating myths of womanhood by dismissing reports of menstrual pain and suggesting that menstruation is expected to be painful. Those patients seeking a diagnosis for their pain are the ones who suffer the consequences.

As the interviewees in my sample report, pain with menstruation is often ignored, dismissed, or in contradiction to the silencing of menstruator's reports of pain, it is often written off as expected and "normal." Uniquely, listening to people living with endometriosis explain the correlation between their endo pain and experience going through labor emphasizes the levels of pain women are expected to manage in silence. Grace, also shared a story that expounds what endometriosis pain can feel like:

> I had to miss a lot of school. I remember being gaslighted, about my pain about people not understanding. And it's not even listening. Like she's being dramatic. And it's like, no, I'm in so much pain to where I actually ended up pregnant at sixteen. And I had my daughter at seventeen…I started feeling cramped. And thank God I was at work. And like, every few minutes, I was feeling cramps and someone asked me at work, like, 'Are you okay?' I was like, 'I just keep cramping.' She's like, 'Those are contractions.' And I was like, wow, those are contractions? And I called the doctor and they're like, you need to go in. And, lo and behold, I was in early labor. They had to give me meds to stop it. I had to go on bedrest. It was pretty serious… And sometimes, like it's stronger than labor now.

Debilitating endometriosis pain can lead people to misinterpret pregnancy and labor pains, downplay their symptoms, and overlook what requires immediate medical intervention. In Grace's experience, it was not until her coworker helped her realize that she was experiencing contractions that she sought medical attention. We can imagine other instances in which someone who lives with endometriosis pain is not able to recognize labor pains, and thus they are put into dangerous situations for themselves and their baby's health. The example of blurred lines between people's endo pain and labor pains is twofold. First, we learn more about the severity of endo pain and secondly, we can see the human cost of suffering associated with a disease that often takes many years to diagnose.

The cultural link between menstruation and womanhood contradicts conceptualizations of reproduction as power. The negative connotations associated with monthly bleeding devalue its direct relationship to the potential for reproduction. The contradiction of woman as the mother who endures life's greatest pain and who is the weak, feminine, gentler of the genders informs the same type of double-standards we see when it comes to cultural myths associated with menstruation. On the one hand, pain with menstruation is taught as something one can expect. On the other hand, when women report painful symptoms associated with menstruation, they are often dismissed, considered to be exaggerating, or told that their pain is all in their head.

It is not just in medical appointments that people with endometriosis face disbelief. Grace shared how she often had to skip or leave school early because of her symptoms and that nobody would take her seriously. Then, even at home, her parents did not understand what she was going through. Grace said:

> And you know, there have been times where I was at school and in pain. Just times, you know, where I even told the teacher like 'I have to lay down. I don't feel good.' Like, I'm you know, breathing heavy because I'm in so much pain, and them telling me like 'You can't go to the office.' But by the time I was in high school, I really was like, you can't tell me what to do either. And I live so close to my school, I would walk home. 'Fine. Call! Call the officer, I don't care. I'm in pain and no one's listening to me.' But I would literally walk home from school because it was like, it hurts so bad and no one cares. And I need to lay down. Or like you know? My mom does like, they don't hear me, you're not hearing me. I'm in pain.

As Grace shared, it can be frustrating when people do not listen or believe someone's symptoms, which creates major challenges. For people as young as high schoolers, the common myth that menstrual pain is "normal" can lead ill persons with endo to be dismissed and forced to manage their pain and suffering. The inability for outsiders to believe in the pain experienced by people with endo can cause feelings of isolation when someone with endo tries to express what is happening and the people around delegitimize their experience.

The dismissal of endo symptoms cause distrust in doctors. As Alyssa, a 30-year-old from California shared, there is a sense that endometriosis pain, or pain with menstruation in general is, "something that women made up. 'Boo hoo hoo, I'm taking time off.' You know?" Menstrual pain has been portrayed as normal to a fault, so that many physicians and medical practitioners do not get concerned when their patients report severe pain between and during their cycles. Like in other interviews, Alyssa shared that the pain she experienced from endometriosis is real and that it is not something that women make up. More importantly, Alyssa added:

> You know, it's real. And doctors need to take us real, you know? Take us seriously! You know? Because I shouldn't have to have the thought in my mind of like, ‘Oh, he's not he's not taking me seriously. He's just thinking I'm after more pain pills, you know, pain drugs.’ Maybe, okay. Maybe I am. I was after more pain drugs, because I knew, you know? My endo was bad. But that’s not the point. I, what I was truly wanting was a diagnosis, next steps.

Patients should not wonder if their doctors are taking them seriously. Alyssa knew that she was suffering, yet she had to wonder whether her doctor was going to help her identify the cause of her symptoms. While doctors hold a place of authority, in which we look to them as experts with the information we need, they do not reciprocate that respect to patients and often, the reports by endo patients are not valued as viable medical expertise.

While the number of endometriosis experts continues to grow, there remain deeply entrenched cultural ideologies, such as the idea that menstrual pain is normal or that women often exaggerate their symptoms, that misinform many practicing doctors. Medical gender bias can impede doctors’ recognition of early signs of endometriosis. However, some medical experts are trying to disrupt the false narratives about menstrual pain, improve endometriosis care, and disrupt the trends in delayed diagnosis. Recently there has been a growing pool of endometriosis specialists who have invested their life’s work to understanding, diagnosing, treating, and educating about endometriosis. Some endometriosis specialists acknowledge the significance of menstrual pain in the diagnosis of endometriosis. According to Dr. Tamer Seckin, a deep excision specialist and co-founder of the Endometriosis Foundation of America, “A painful period is the first cardinal symptom of endometriosis.”[75] It has been reported that up to two thirds of women who suffer from endometriosis experienced symptoms before the age of twenty.[76] However, there remain countless reports of women getting medically gaslighted by

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[75] Tamer Seckin, *The Doctor Will See You Now: Recognizing and Treating Endometriosis*, (Nashville, Tennessee: Turner, 2016), 43-44.

[76] Cook, *Stop Endometriosis and Pelvic Pain*, 35.

their doctors. For example, when patients with endo say that they are experiencing severe pain associated with menstruation, often their doctors dismiss them or insinuate that it is actually the patient who is making up the symptoms, not an underlying health concern.

In the United States menstrual pain has been construed as a "normal" part of "womanhood." Ideology that menstrual pain is normal disrupts the recognition of the often-debilitating symptoms associated with endometriosis. Dr. Andrew S. Cook, a women's health expert who specializes in the treatment of endometriosis, argues that endometriosis is one of the most painful medical conditions and shares that patients describe the pain associated with endo as, "knifelike, burning, tearing, hot, sharp, and even worse than childbirth."[77] Although not every person living with endometriosis experiences pain, it is one of the most common symptoms. Normalizing pain is damaging to those seeking treatment because they may form a skewed perception about what they should expect or second guess themselves.

The dismissal of endometriosis pain is not always specifically related to menstruation. One participant, Sophia, a 37-year-old from California shared that when she reported her severe pain during intercourse to her doctor, the doctor responded, "You should just probably drink. Have some wine if you want to have sex with your husband. Oh, it's normal. Most women go through this. You need to talk to a psychologist because I think you're really anxious." Sophia's example of how the doctor dismissed her pain, suggesting that it is both normal and expected that women will endure this, coupled with comments that Sophia was anxious, leads back to a history of the medical dismissal of women's physical pain as hysteria or psychologically based. According to the interviewees in my sample, those who do report their menstrual-related

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[77] Cook, *Stop Endometriosis and Pelvic Pain,* 121.

symptoms to doctors are often quickly dismissed. Thus, their doctors reify the idea that patients should stay silent about their suffering related to reproductive health because it is "normal."

Often, the misconceptions of pain as part of menstruation contributes to a sense that when folks complain of menstruation as painful, they are dramatizing their experience or looking for drug therapies. Nancy Arden McHugh reports in *The Limits of Knowledge* that, "Women who complained of pain were viewed to be neurotic, nervous, frigid, exaggerating their symptoms, or having a low tolerance for pain."[78] Dismissing symptoms without formal investigation leads patients to think of their pain as normal. Normalizing pain can lead to years of suffering because the sufferer assumes that there is nothing left to be done to improve their condition. Additionally, the fear of being misconstrued as exaggerating one's pain can lead women with endo to downplay their symptoms.[79]

The first apparent barrier to an endometriosis diagnosis is the dismissal of menstrual pain as a symptom. Due to myths normalizing menstrual pain, there is an inability to make connections between how menstrual pain acts as a symptom of an underlying illness. I theorize that because so many doctors do not form the connection between menstrual pain and endo, there remains a delay in diagnosis for most endo patients. Whether doctors disbelieve that their patient feels the symptoms they are reporting or dismisses their pain as "all in their head" doctors participate in perpetuating harmful myths or cultural assumptions that disrupt the medical process of diagnosing the disease.

Myths of Menstrual Pain as "All in Their Head"

Across my sample, there are many instances in which participants share that their doctor told them that "It's all in your head," or that they were, "too dramatic," "a baby," or

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[78] McHugh, *The Limits of Knowledge*, 25.

[79] Cook, *Stop Endometriosis and Pelvic Pain,* 35.

"exaggerating their pain." It is difficult to imagine why someone would explain away another's pain. When patients are advised that their physical symptoms are in their thoughts and ideas, the ill person is pressured into feeling like it is somehow their fault that they are sick. The endometriosis patient narratives from my sample demonstrate the pattern of doctor dismissal leading to a concern that they did bring this upon themselves. The phenomenon of endo patients feeling at fault for their sickness echoes sentiments shared by Susan Sontag in *Illness as Metaphor*, in which Sontag says, "Psychological theories of illness are a powerful means of placing the blame on the ill. Patients who are instructed that they have, unwittingly, caused their disease are also being made to feel that they have deserved it."[80] The complex inner turmoil of trying to understand why one is sick and what their diagnosis is in the face of dismissive medical encounters is challenging.

Determining that a patient is exaggerating their symptoms is ineffective and an exclusionary means of stereotyping patients. Dr. Cook says, "Families and physicians should never believe that a girl's pain is exaggerated or normal."[81] The key here is that pain is not normal. Pain is a signal to our brain, letting us know something is out of balance or needs to heal. However, common tropes that pain with menstruation should be expected lead to a dismissal of women who share that they are experiencing painful symptoms related to menstruation.

Endometriosis literature has well-established the fact that there persists a myth that pain is "all in their head."[82] Gaslighting patients by telling them that their physical pain is imagined and that their mind is the cause of their deep, throbbing, chronic discomfort is a damaging

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[80] Susan Sontag, *Illness as Metaphor & Aids and its Metaphors,* (New York: Penguin Books, 1991), 58.
[81] Cook, *Stop Endometriosis and Pelvic Pain,* 35.
[82] Cook, *Stop Endometriosis and Pelvic Pain,* 34; Seckin, *The Doctor Will See You Now,* 3; Helen Cox et al., "Focus Group Study of Endometriosis: Struggle, Loss and the Medical Merry-Go-Round," (*International Journal of Nursing Practice*, vol. 9, no. 1, 2003), 7.

dismissal of the real experiences of those living with endo. In the following examples, I add nuance to the claims that people with endometriosis are told that their pain is "all in their head" by emphasizing discussions with participants that show how such accusations occur and what they mean for the patient.

Endometriosis and Invisible Disability

Endometriosis is difficult to understand because one cannot see the cause of pain without advanced medical equipment. The inability to see someone with endo's pain, such as viewing a person with a laceration or broken arm, makes it, "all too easy for people to blame the woman, not the disease—and for the woman to blame herself, against all reason, for not getting better."[83] The invisibility of endo complicates the process of diagnosis for both doctors and patients. Endometriosis is most often diagnosed through ruling out other causes, thus the diagnosis is crafted through a series of tests that indicate what is not there, rather than a clear marker of the presence of endo. Since endometriosis can only be surgically diagnosed through laparoscopy and sending samples to pathological testing to confirm that the extracted cells are endometriosis, many doctors avoid jumping to conclusions and spend time ruling out other possibilities first. The inability to visualize the cause of pain without skilled surgical intervention results in a pattern of women who are not taken seriously when they report their painful symptoms associated with endometriosis because of a false sense that the patient is exaggerating.

Not defined by any externally visible symptoms, endometriosis is further complicated by its hidden, phantom-like quality. The pattern of dismissal of debilitating endometriosis symptoms coupled with the invisibility of the disease has led some participants to discuss the link between endometriosis and disability.

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[83] Cook, *Stop Endometriosis and Pelvic Pain,* 13.

As a chronic illness, endometriosis participant accounts illuminate the complex nature of how the disease shapes the experiences of people living with it. Sophia, the 37-year-old from California said that everybody's experience with endo differs, so a diagnosis of endo does not necessarily mean disability. However, she added:

> If you look at the severity of how it effects women…if you look at the definition—they either call it debilitating or disabling condition…well by definition it is disabling so, why isn't it a disability? So, I feel it should be. I can see why not knowing when I was younger maybe allowed me to achieve things I might not have achieved had I known…but I struggle with that— whether it would have been nicer to know or not.

Sophia expresses concern regarding how calling endometriosis a disability might have restricted her achievement in some ways. Sophia's concerns align with prevalent expectations of the limits of disability that are informed by the construction of expectations for able bodied individuals. Thus, Sophia learned dominant cultural beliefs about disability and filters her perception of the relationship between endometriosis and disability through a hegemonic lens. Regardless, Sophia suggests that, by definition, endo should fall into the category of disability.

Kylie, a 41-year-old from North Carolina also vocalizes why endometriosis can be seen as a disability:

> It is debilitating. It is anxiety producing. It prevents me from having like a super, really full life…It feels like a disability. Like it really feels like a disability. I don't say that lightly that it feels like a disability. Because I am debilitated from doing anything else during that time. But it's also weird because it's like this cultural expectation that you grin and bear it when you're having your period, so it's just that, it's exhausting just mentally. Like okay, I gotta go face the world and pretend like nothing's wrong when in fact I'm just so miserable.

Like Sophia, Kylie suggests that endometriosis should be seen as a disability due to its debilitating nature. In both cases, we are hearing from individuals who have lived with endometriosis symptoms for over two decades who share that the status of endometriosis as a disability deserves a reevaluation. Sophia and Kylie express that the condition has disabled them at times and that they are misled because it is not formally recognized as a disability. The lack of recognition as a disability complicates the barriers that people living with endometriosis experience because they are forced to navigate a disabling condition without similar accommodations to those provided for people living with like challenges.

Since endometriosis is not an externally visible illness, it has direct ties to the types of challenges faced by folks suffering from other invisible chronic illnesses or invisible disabilities. The relationship between illness and disability is problematic within disabilities studies. In "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," Susan Wendell discusses the differences between healthy disabled and unhealthy disabled persons, of which their disability is an effect of chronic disease.[84] Women suffer ill health at higher rates than men and are more likely to be disabled by chronic illnesses.[85] Although endometriosis is not classified as a disability, for some, the symptoms become debilitating and prevent them from participating in their daily activities. For example, as Young says in "Disability and the Definition of Work," pain and fatigue can limit someone with endo's ability to complete tasks at work, leading employers to consider them, "lazy, slackers, uncooperative or otherwise inadequate."[86] Like invisible disabilities, outsiders struggle to understand that people with endo are sick or suffering when there is not visual proof to validate the onlooker's ideas of what illness "looks like." Due to the hidden nature of endometriosis, like other chronic illnesses, there is an ability to pass as healthy. Wendell says there are times when someone's disability continues to be disbelieved because it is not externally presented, which means the person is "passing." Wendell adds, "Passing is sometimes voluntary, but it can also be involuntary, in that some of us will be

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[84] Susan Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *(Hypatia*:16, no. 4, 2001), 19.
[85] Wendell, "Unhealthy Disabled," 19.
[86] Iris Marion Young, "Disability and the definition of work" in *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions*, (New York: Routledge, 2000), 172.

perceived as nondisabled unless we draw attention to our disability, and sometimes even after we draw attention to it."[87] Since endometriosis cannot be seen with the naked eye, it generates a lack of empathy from outsiders who assume that the person with endometriosis is not sick or disabled, which replicates to the issues of assuming endo is "all in their head." The invisibility of endometriosis causes outsiders to assume that people with endo are not sick.

The examples from my sample regarding the need to change the status of endometriosis to be classified as a disability are substantiated by recent endometriosis disabilities studies scholarship. In "The Pain of Endo Existence," Cara E. Jones argues that a feminist disabilities reading of endometriosis is necessary to develop theories of pain that better accommodate the disabilities associated with endometriosis because "the pain of endometriosis is in itself disabling."[88] Further, Jones argues that, "We must understand endometriosis as a disability rather than a privately managed, female problem," because otherwise social beliefs construe endo as, "an obstacle for individuals to overcome through perseverance, effort, and informed decision-making."[89] Similar to the dismissal of endometriosis pain as normal or "all in their head," the prevailing ideas that endometriosis is not a disability causes additional cultural barriers for the folks seeking a diagnosis.

<u>On Self-Doubt</u>

Since so many conflicting narratives regarding menstrual symptoms proliferate, participants reported different experiences with self-identifying as ill or vocalizing their experiences with endometriosis symptoms to others. Sophia, shared with me that she viewed endometriosis as such a severe diagnosis, that despite her many symptoms, she did not believe

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[87] Wendell, "Unhealthy Disabled," 29.

[88] Cara E. Jones, "The Pain of Endo Existence: Toward a Feminist Disability Studies Reading of Endometriosis," (*Hypatia* 31, no. 3, 2016), 555.

[89] Jones, "The Pain of Endo Existence," 567.

she “qualified” as someone who might be diagnosed with endo. She explains that she heard the term endometriosis in college and that:

> …ever since then it was like this thing. Like, it's funny. It was like, oh, like, you're such a baby. Because women with endometriosis, they're the ones who are really suffering. So, stop complaining about your period pain, you don't have that. Like, they, they're the ones like they're the ones…those women are the women who are really suffering. And, so, if you're not one of them, like why are you acting like such a baby?

Here, we see how the rhetoric around endometriosis and painful menstruation can lead to a sense that it would be impossible to experience that level of severity. For Sophia, she imagined endometriosis as a high standard of pain, of which she could not claim to experience herself-barring her from pursuing a diagnosis until later, when her symptoms became unmanageable.

Peyton, a 23-year-old Hispanic woman from Washington, told me that she was quicker to claim the experience, and that she, “would try to bring this up to anyone and everyone! And everyone would say ‘you're overreacting, you don't know what you're talking about,’ or ‘I've never experienced that.’” So, when she did share that she was suffering, people dismissed her as overreacting, or they did not acknowledge her symptoms because they could not relate to the experience. Peyton added:

> It is so isolating and so painful on so many different levels, you have the physical pain, but then you also have the mental pain of like, my body is constantly in pain. What do I do with this? But then you also have the emotional pain of like, I'm being rejected at every turn. Am I crazy? Is there something wrong with me? And not wrong with me? Like, I felt like I was going insane for the longest, longest time and it was just me in my head. Because no one would listen to me. No one took me seriously. And everyone told me I was overreacting, couldn't handle it.

When people with endometriosis are repeatedly told that they are overreacting or that their pain is not as bad as they are saying, it can be confusing. Often, the dismissal leads endometriosis patients to believe that perhaps they are exaggerating or that what they are feeling is not quite what it seems.

In both of these examples, we can see how people with endometriosis are often living with an awareness that the severe pain they are experiencing is notable. Then, when they tell their doctor, friends, or family, the responses that what they are experiencing could not be that bad lead folks living with endometriosis to question themselves. They wonder if what they are experiencing is not as bad as they initially feel. They wonder if perhaps they are weak and that this is just how periods are. Unfortunately, examples of medical gaslighting are common and can be a factor that delays the diagnosis of people with endo because they start to distrust themselves and believe that there is not something wrong with them.

On Prescription Pain Medications

The ongoing dismissal of an individual's reports of pain symptoms can result in patients believing that that are being dramatic and that their symptoms are not as bad as they feel. The sense that they are exaggerating is complicated when the patient is prescribed medications used to treat severe pain, giving the patient mixed messages about whether what they are feeling is real. Jade, the 42-year-old healthcare worker from California mentioned earlier, says:

> Yeah, I don't understand how men—how any doctor—can look at a woman and tell a woman that this is normal. 'I'm so sorry. You're just being, you're being dramatic.' That was something I was always categorized as: being very dramatic. Don't get me wrong. I have a flair for drama. Just my personality, but there are certain things I don't mess around with. And I honestly, even into my early thirties, I just thought I was dramatic. And I was delicate. And I was being you know over the top about things. I was gaslighting myself.

For Jade, having multiple doctors tell her that her pain was normal led to self-doubt, in which she started to believe that the pain she experienced felt severe because she was fragile and overexaggerating her experience. Jade is a White woman, which is worth noting because she was prescribed narcotics for pain management and as I will discuss later, some participants of color shared that doctors would refuse prescription pain medications to treat their endo symptoms.

Jade explained that she received a standing prescription for Norco at age fifteen because of the severity of her pain. She said that in addition to her doctor writing her a script, the doctor also insisted that, "it was just because I was a baby. Just my pain levels were so low that I just couldn't, I couldn't handle it. So, he gave me a prescription for Norco. Just to get me through because I was so delicate." Talking down to a patient who requires opioids to manage their pain and explaining that they are just sensitive to pain demonstrates the challenges that endo patients face while seeking diagnosis. NORCO is a brand of Hydrocodone Bitartrate and Acetaminophen Tablets. According to the U.S. Food and Drug Administration approved Medication Guide, "NORCO is indicated for the management of pain severe enough to require an opioid analgesic and for which alternative treatments are inadequate."[90] When a doctor prescribes any opioid, it is because a patient is unable to find relief using other over-the-counter medications. Although this doctor was willing to write the prescription, they maintained that it was because the patient was "delicate," not because the patient's pain was real. This creates misunderstandings for the patient, who starts to believe that they were just weak and that the pain they experienced was not as bad as they had thought.

Similarly, Kendall, a 30-year-old White woman from Massachusetts shared how opioids were the only way to manage her pain and so she became dependent at an early age:

> It did get to a point where my parents had a ton of surgeries growing up. So, we always had opioids in the house. So, I would be taking these thousands of milligrams (of acetaminophen or ibuprofen), like every six hours, and it still wouldn't be enough to impact my pain that I was like, well, these drugs make my mom and dad feel really good. So, and they're always offering them out to other people. So, what if I just took a couple and then next thing I know, they're having to refill their prescriptions because all the pills would be gone because I took them. I got addicted to opioids at like thirteen/fourteen because it was the only thing that impacted my pain. I don't know what they were. Honestly, I just know that they were prescribed because my parents were having

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[90] The United States Food and Drug Administration, (Review of *NORCO® Hydrocodone Bitartrate and Acetaminophen Tablets, USP 5 Mg/325 Mg CII*. 2019), https://www.accessdata.fda.gov/drugsatfda_docs/label/2019/040099s023lbl.pdf.

> surgeries after surgery. So, it wasn't a red flag that they were having to be refilled. But the accessibility is honestly what got me. So, when I was sixteen and finally went to a gynecologist for the first time, I was like, 'Well, can I get these magic pills?' And they're like, 'No, but like we'll give you opiates adjacent.' So, I know Tramadol is supposed to be like not addictive. But I've refilled my Tramadol prescription maybe twenty-five times. They were always happy to give me pills to shut me up. But never to actually listen to the problem. So, I have brought up my painful periods to every single medical provider.

Although Kendall shared that she brought up her symptoms to every provider, she experienced years of not being heard by her doctors. The prevalence of opioid use by people with endometriosis should signal to doctors that the pain is severe. When the medication prescribed by doctors is not enough to manage the symptoms, often folks feel that they need to take matters into their own hands. To learn that the only way that some patients experience relief from their endometriosis pain symptoms is with opioids combats ideas that the pain they are experiencing is, "normal." Rather, their experiences indicate a need for intervention and deserve exploration for the root cause of their symptoms. However, not all participants reported that their doctors or emergency room staff would provide them with pain medication to manage their symptoms.

Racist Profiling of "Drug Seekers" and Myths of Black Women's Higher Pain Tolerance

For some participants in my sample, the medical dismissal of their symptoms was further complicated by their intersectional identities and the medical racism they experienced because of their race. African-American and biracial participants reported that their race is implicit in the mistreatment they experienced by medical practitioners, with participants sharing examples such as doctors asking them explicitly, "Do you use drugs?" a presumptuous question indicating expectations that Black patients reporting pain were more likely drug seekers. The Association of American Medical Colleges reported that African Americans are administered pain medication 22 percent less often than White patients and about 50 percent of White medically trained professionals believe African Americans have thicker skin or less sensitive nerve endings than

White folks.[91] Stereotyping African Americans as drug seekers or as having a higher pain tolerance has implications in the long delay that people with endometriosis experience when seeking diagnosis.

Tanya, a 37-year-old African American woman from Mississippi, shared an instance of being stereotyped as a drug seeker. Tanya says, "There were times that I went to the emergency room, clearly in pain, and you know they were like, 'Well I can't give you any drugs. I can't give you anything for the pain.' And so, it's clear that they thought I was just there to get drugs." Unfortunately, racist stereotypes that lead medical workers to assume that Black patients are looking for drugs could also factor into the delay of diagnosis of endo for those patients because doctors overlook the underlying condition, assuming that their Black patients are looking for pain medication. For Tanya, her identity as a Black woman produced her encounters with the medical professionals who made assumptions about her. Despite a long history of visiting hospitals, the emergency room staff assumed Tanya was seeking drugs, when in reality she was seeking relief from undiagnosed endometriosis. The dismissal of symptom reports lead those suffering to assume that their experience is normal, which is worsened when women of color are seen as drug seekers rather than patients in need of care for their symptoms.

In addition to the harmful stereotyping of Tanya as seeking drugs, she additionally faced contradictory messages from her doctors entangled with racist perceptions of African American women as having a higher pain threshold. The distortion of portraying someone's real pain as "normal" leads to misplaced messaging about what one is experiencing and how one should process their lived experience. Tanya shared how she experienced doctors making assumptions about Black women's high pain tolerance. Tanya shared with me, "A lot of doctors feel like

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[91] Janice A. Sabin, "How We Fail Black Patients in Pain," (AAMC, January 6, 2020), https://www.aamc.org/news-insights/how-we-fail-black-patients-pain.

African Americans, or Black individuals, people of color have a higher tolerance for pain than others." The medical double standard of practitioners assuming African Americans have a higher pain tolerance begs the question of why, then, are medical practitioners not concerned when African American patients report debilitating or excruciating pain symptoms? If doctors' roles are to treat patients in pain and discomfort, and a population of folks who are falsely assumed to have a high pain threshold enter the medical office seeking relief for severe pain, then why would doctors ignore these complaints, dismiss them, or refuse treatment? African American people with endo face racial stereotypes that prevent the timely diagnosis of their disease. They are thought to tolerate pain, and so, they face the prevailing myth that when they report pain, it is because they are seeking drugs.

While African American people are assumed to have a higher pain tolerance, they are also disproportionately denied pain medications when seeking medical attention. The outcome of these myths can lead to doctors' dismissal of patients' needs. Then, patients might lose hope that a doctor will ever help. Tanya shared:

> Especially for women of color… I don't know where this notion came from that you know, we have a high tolerance for pain or, you know, that we're drug seekers, or whatever the case may be. But, even now, and this was probably about a year ago, I had followed up with the doctor for surgery and I was still having some issues, you know, down the road, so I called to say, hey is this normal? Is this something I should be concerned about? And she's like, 'Well no it's not normal, you shouldn't be feeling pain at this time. But I can tell you he won't prescribe you anything for it.' And I'm like, that is not even why I was calling. I simply wanted to know is this something that I should be concerned about? But I ended up just not following up at all because I'm like, okay, just from a phone conversation she thinks I'm after drugs, when I clearly still have drugs left over from the actually surgery that I didn't take.

Tanya's experience shows how she was dismissed for her pain, which led her to avoid seeking additional answers from the doctor for her concerns. Thus, due to the cultural incompetence of medical practitioners, we see a patient who needs follow-up and guidance relinquish their trust in the medical system and instead just press on through their discomfort. In a situation where we would otherwise expect a doctor to say, ‘Come in and we will check you out,’ the doctor instead focused on the fact that no additional medication would be administered and dissuaded Tanya from continuing to seek help.

Similarly, Grace, the 30-year-old woman from Illinois previously mentioned, commented on how medical practitioners are taught myths about Black women’s pain threshold that negatively influence their experience seeking endometriosis diagnosis. Grace is biracial with both Black and White heritage. She shared:

> And then to learn that, that in medical school nurses and doctors are being taught that Black women have a higher pain threshold. What because of our history of having to be beaten and enslaved? What does your race have to do with your pain threshold and how much pain you can tolerate? And to be told, like ‘you're being dramatic, you can't be in that much pain.’ Do not tell me what I can and cannot do just because you have not experienced it. It's like this issue of listening of not really listening not hearing what people are saying and writing them off like, ‘They're crazy and they're crazy too. And I guess all these types of people are crazy.’ Again, it’s baffling.

Grace’s comments underscore an additional layer of complexity related to the pervasiveness of cultural myths seeping into medical care. For Black women, the legacy of racism continues to spread misrepresentations of Black women’s pain tolerance that lead doctors to disbelieve Black patients’ reports of pain symptoms. The disbelief in Black women’s reports of pain may impact the delay to diagnosis for these patients.

Another participant explained that in addition to the dismissal of women’s voices, their positionality as a Black woman led to further silencing by medical practitioners. Stacy, a 45-year-old from California said:

> I mean, I think that in regards to Black women, we’re disregarded a lot in the, in, in places of the healthcare field. Is that ‘Oh, you're just you're being dramatic or it's not that serious.’ And for me, luckily, I had a doctor who identifies as half Black and half Mexican that so when I started saying, ‘Hey, these cycles are really well, not my cycles, but I'm having all these different problems,’ and that she was able to go dig deeper. But I mean, growing— and I also think it's the environment she grew up into. She like grew up in Utah. It's a predominantly White state, and so you're not seeing any doctor from ethnic backgrounds or diverse background, so that the fact of the matter. So, a lot of times that I would get misdiagnosed with a lot of different things from it being a common cold to the flu. So, when it came to my cycle, they, there was no real listening of that.

Stacy’s comments highlight the distinct ways in which the intersectional identity of someone seeking a diagnosis for endometriosis can shape their experience seeking diagnosis. Stacy shares that her race was part of the reason she was misdiagnosed for many years. Similarly, Grace shared that the conceptualization of endometriosis as a White woman’s disease is detrimental to all women of color with endo seeking a diagnosis, adding, “So when you're a woman, but you're also a woman of color, it just makes it even worse.” Thus, participants in the sample who identify as women of color emphasize that their intersectional identity further complicated their road to diagnosis.

Finding Someone Who Listens

Dissimilar to their experiences dealing with medical experts, some participants shared the positive impact of participating in the endometriosis community. Some engage through social media or the MyEndometriosisTeam website. Mia, a 38-year-old from Illinois shared how participating in online spaces has been beneficial to her sense of belonging:

> I'm really seen and heard by other women in the endometriosis community, I think my story is, in some respects, all too common, and everyone has their own unique story, but there are parallels and one of the parallels I've come to learn is having doctors give you the wrong information or to dismiss you.

Whereas doctors are sought for their expertise, with commonly misdiagnosed illness, like endometriosis, those who share the common thread of symptoms and experiences are often well-equipped to share pain management methods, stories, experiences, and advice to support one another through coping and healing. As I will explore in a later chapter, the shift to self-education and community education tends to be common amongst the people I interviewed, all of which received an endometriosis diagnosis. In many cases, myself included, it was not until the patient addresses their healthcare provider with the suspicion that what they are experiencing is endometriosis that the healthcare provider pursued further investigation into whether endometriosis was present.

Whether there are misconceptions about invisible illness as a disability, or racist assumptions about patients' desire for drugs when seeking treatment, the pattern of patient dismissal by medical professionals who told them that their pain is "all in their head" can lead patients to believe that their suffering is imagined or self-induced. Fearful of gaining a reputation as making up their experience, perhaps they stop visiting doctors and start to believe that each cramp or sharp pain, is just something they have thought up. My findings corroborate claims from endo specialist Dr. Cook, who says that when people with endometriosis speak openly about their pain, they are "too often accused of being complainers, hypochondriacs, or drug seekers."[92] Some patients struggle with the conflicting sense that the symptoms they are experiencing are not real. Alternatively, when a patient's pain is dismissed, that dismissal can contribute to a skepticism of medical treatment, eroding a patient's trust in doctors or the medical establishment. Sometimes the distrust will prompt a patient to seek a second, third, or fourth opinion from other doctors or specialists, and in other cases it dissuades patients from seeking additional medical support. They might lose faith in medicine entirely. The dismissal not only erodes trust in the doctors but can also lead to a loss of trust in oneself, or a loss in one's

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[92] Cook, *Stop Endometriosis and Pelvic Pain*, 122.

connection to their own body. As I have demonstrated through the examples thus far, the dismissal of endo patient reports of pain as “all in their head,” is a cultural phenomenon implicit in the delayed diagnosis of endo.

Pain is Not Normal

Hearing the detailed experiences of people who have been diagnosed with endometriosis gives perspective to how living with an undiagnosed disease can impact one’s physical and mental health. Pain is not normal. As Tanya, said:

> That you're having painful, debilitating periods- it's not normal. You know, I wish I had known just about endo in general. And that's not something that I learned in school. It's, I mean, even in college, it's not anything that I have ever heard of. So, I just wish it was more talked about. It becomes a household name because so many young girls need to know that when they start experiencing this kind of thing. It's not known that no matter how many people say, ‘Oh, it's normal.’ It's not.

Participants shared that they were told again and again how their experience with menstrual pain was normal. For years the doctors that the participants confided in tried to convince them that it was normal. When someone is dismissed many times in search of a diagnosis, they might lose stamina to continue tending to medical appointments or simply internalize the idea that their experience is typical. Thus, the dismissal of pain as “normal” or claims that pain is “all in their head” are factors that might contribute to the lengthy delay to endometriosis diagnosis.

Endometriosis and Fertility

The doctor’s office is a highly politicized space. Although many expect to enter a doctor’s office to get clear answers about why they are suffering, there are differing approaches to folks seeking endometriosis diagnosis depending on whether their main concern is pain or struggles with fertility challenges. When we appeal to a medical expert’s opinion, we assume that they will focus on treating the root cause and center our health outcomes as the primary goal. However, in many instances, there is a different emphasis on supporting women to reproduce when endometriosis is present than there is to support women to find relief from their pain and other unwanted symptoms because, as Elanor Thom says in *Private Parts*, "fertility is often presented as the main issue and doctors tend to talk about this more than any of the other symptoms."[93] When appealing to reproduction as opposed to women's health, the messaging from expert's implies that a women's reproductive capacity is more important than her comfort.

The connection between fertility and endometriosis is a loaded example of how insidious the gendered expectations of womanhood are in relationship to women seeking a diagnosis for reproductive health issues. Although much of this chapter has focused on how menstrual pain has been normalized and women have been dismissed for reporting their pain symptoms related to endometriosis, there are many endo patients who do not experience pain. Rather, these patients suffer when they are trying to conceive and encounter fertility challenges. Endometriosis is found in up to 50 percent of infertile women.[94] An estimated 30 to 50 percent of people diagnosed with endometriosis experience infertility.[95] Consistent with the broader trends, within my sample, ten participants or 55.6 percent of the sample reported that they struggled with infertility. What is alarming, is that when women approach their doctor with the goal to treat their fertility— not their pain— associated with endometriosis, the response tends to be more proactive. Some people with endometriosis do not experience any endo symptoms except for fertility challenges, so their road to treatment can look quite different. The implications are that doctors approach fertility as more important to treat than patients seeking relief from pain, representing gendered assumptions that women's role to reproduce is more valuable than a

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[93] Elanor Thom, *Private Parts: How to really live with endometriosis,* (Great Britain: Coronet, 2019), 229.

[94] Seckin, *The Doctor Will See You Now,* 62.

[95] Kerry-Ann Morris, *Living Well with Endometriosis: What Your Doctor Doesn't Tell You…That You Need to Know*, (New York: Collins, 2006), 174; Kate Seear, *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*, (New York: Routledge, 2014), 5.

woman having a good quality of life as an individual. It is not as straightforward as merely suggesting that doctors start to listen and acknowledge their patients' symptoms, because sometimes, the cultural coding can lead folks struggling with endo to refrain from reporting their symptoms. Valerie, a 31-year-old from California shared:

> I always think back, my mom was very pro being healthy and going to the doctor. And I wish that I would have complained more to her because I'm thinking, I wonder if I would have gotten diagnosed when I was a teen, I might be able to be a mom now. And I think about that a lot. That waiting time, and then the progression of it, the aggressiveness of it. Those three years maybe it could have, you know, like, what if it wouldn't have gotten everywhere? Like, what would I have done? I was waiting around for these damn doctors, because they can't figure out what it is. And yet my body's at war with itself, you know?

Due to the assumptions that she should not complain too much to her mother about her menstrual-related symptoms, Valerie now wonders whether an earlier diagnosis could have led to better fertility in the long run. Endometriosis is a progressive disease, so early intervention can make a big difference for long-term outcomes. The delay to get diagnosed and treated may be a factor at play in Valerie's struggle to conceive. When the progression of endometriosis leads to fertility challenges, it becomes very difficult to manage the emotional and mental impact that not being heard has had on a patient. While suffering from pain carries its own weight, the inability to conceive when one wishes to parent adds an additional layer to the injustices experienced by endo patients who have been told that nothing is wrong with them by medical practitioners.

Whether a patient is seeking diagnosis to treat their pain or their fertility challenges, the concerns should be valued equally. In both cases, the outcome has a direct impact on the patient's quality of life. However, in many cases there seems to be an additional value ascribed to people seeking endometriosis diagnosis due to fertility challenges. Sophia said:

> It would be nice to know if there was a way that women could just be seen. Not as baby makers with endometriosis, but as human beings with a condition. And not to minimize, but to not have that be such a driving force in seeing if care is even needed or warranted in the first place. Because a lot of these studies are done under fertility grants and things like that.

Sophia's concerns are valid and it is an important point that the treatment of endo should not be reserved to those who are trying to reproduce. When an illness that predominantly impacts women is treated primarily on the basis of fertility, it reinscribes the cultural role of woman as mother and that their capacity to reproduce outweighs the need for women to live healthy and productive lives outside of motherhood.

One participant shared that her doctor's fixation on family planning made her uncomfortable during her appointments to address her pain. Brooke, a 27-year-old White woman from Massachusetts shared:

> Every time I go see him; he asks about my family planning. And then he says, well, you know, 'I really think you should have a baby.' And one of the treatments that he has spoken about is to cure, for the time being, endo is to have a baby because it will give, maybe I don't fully understand, but it'll give the estrogen something else to feed on. Something along those lines. I think I don't fully understand the science behind it. But he sometimes will push it very hard. So, that is quite literally something that we talk about every single time. And it's a little frustrating. And sometimes I get to the point where I just want to tell him like, 'Nope, not planning on it. Like what's the next option? Let's talk about that.' Because I think he wrote it down on this sheet and the other one like, he'll be like, 'baby,' 'question mark,' 'question mark.'

The pressure to reproduce is a common and uncomfortable cultural phenomenon that can make a patient feel unseen. When a doctor continually circles back to the question of family planning, it again sends messaging that this is the only reason to address endo. Additionally, there has been a history of doctors telling their endometriosis patients that getting pregnant will help relieve their symptoms, which might be true temporarily due to the changes in hormones, but a pregnancy only offers temporary relief. To treat endometriosis, a surgery is required, because long-term relief relies on the removal of the disease. Doctors' use of gender as a framework through which to evaluate treatment of patients is fraught with reproductive injustice, as the focus is making a socially constructed “good woman” over a biologically and physically healthy person. The imposition of gender roles on patients by their doctors can lead doctors towards recommending women get pregnant as part of their treatment for endometriosis, even though the prescription is not scientifically based and echoes sentiments of the early conception of endometriosis as the “career woman’s disease.”

The pressure from doctors for patients to reproduce was not consistent across the sample. Lilly, a 33-year-old African American woman from Texas shared that her doctor recommended drug therapy to put her into menopause for six months to manage her symptoms. While the medically induced menopause stopped her periods and led to some temporary relief from the pain, medically induced menopause is only a temporary treatment option. After the six-month treatment, Lilly started her cycle again and the pain was still unmanageable. Lilly recounted her conversation with the doctor, “He was like ‘Yeah, we can do a hysterectomy.’ And I was like, ‘Sir, I am twenty-one.’ And said it with a straight face and I just hung up the phone and I never spoke with that man again.” Later in our conversation Lilly added:

> I fully believe that if I was a White woman my doctor would not have suggested that I get a hysterectomy at age twenty-one. And it's one of the reasons why, like, I seek out women of color for doctors because I feel like my concerns of not being not validated, but, what is the word? Not appreciated either.”

Lilly’s story shows how the recommendations of doctors regarding endometriosis and fertility are not always in alignment. While one example cannot capture a broad understanding how race factors into doctors’ treatment recommendations, Lilly critiques her experience with the doctor as tied to her intersectional identity as a Black woman, claiming that the doctor would not have shared the same recommendation if she was White.

Of course, everyone's endometriosis experience is different, and some people are seeking relief whereas others are seeking fertility assistance. In some cases, the struggle to conceive can be debilitating to one's emotional state. I was moved to tears when Mia, the 38-year-old from Illinois shared with me the sense of loss associated with endometriosis fertility challenges:

> Um, my personal experience living with endometriosis is like living with a silent killer. We, we honor people who have passed away through cultural practices, we mourn together for adults, children and babies who have died by holding services and coming together. And we don't do that when a baby has never been conceived. We don't do that when a baby has never been born. But it is a loss, and grieving is necessary. And because we don't have the cultural practices around infertility to support grieving families we're isolated. And we're left feeling alone, and we're left having to deal with it by ourselves. So yeah, I very much feel like my children have been taken from me.

Mia did not know that she had any reproductive health issues until she was trying to conceive. Unlike many endometriosis patients who suffer from heavy, prolonged bleeding, and various other symptoms such as pain, Mia is the only participant from the sample who was diagnosed because of her journey with fertility struggles. This is to say, in some cases, endometriosis is directly tied to fertility and can pose challenges for want-to-be-parents. Thus, the treatment of endometriosis needs to be standardized, regardless of the patient's goals. The many examples from my interviews demonstrate the array of reactions by people with endometriosis to its connection to fertility.

The emphasis on treating endometriosis for women seeking to conceive or asking women with endometriosis symptoms about their family planning goals develops messaging that womanhood and fertility are inherently linked, and that fertility is the only reason to treat endometriosis. In these cases, it appears that the emotional pain women endure when struggling to conceive takes precedent over the physical symptoms others might wish to address. Since doctors seem to take concerns more seriously when a woman expresses their desire to get pregnant, there is a dichotomy of physical and emotional pain that hierarchizes the treatment of reproductive illness for the purposes of fertility as the most important goal. The examples indicate that women's cultural capital is tied to their role in reproduction. Doctors do not tend to have the same response when women say that their pain is keeping them from work. While there is in fact a link between endometriosis and fertility, this connection should not be the entry point for doctors to listen, care, and treat endometriosis.

The examples discussed throughout this chapter indicate how doctors sustain gatekeeping practices over medical epistemology by excluding patients from knowledge making processes. Although many medical practices claim their commitment to social justice, which suggests that all members of the community share what Patricia Hill Collins describes as, "equitable access to testimonial recognition," what we actually see is that "interpretive communities regulate and reproduce relationships of unequal epistemic agency among group members."[96] Epistemic violence is committed through the silencing of marginalized knowers.[97] The constant silencing that patients experience by their doctors who dismiss the patient's concerns represent the impact of being silenced by people in power, thus "…quickly learning the protections of self-censorship."[98] The many examples centering the voices of people diagnosed with endometriosis shifts the expertise to patients, an attempt at epistemic justice, amplifying patient accounts as valuable in addressing what we do not know about endometriosis.

Shifting Expectations Regarding Women's Pain

The perpetual dismissal of endometriosis patients results in silencing of patient experiences that prolong their suffering and deter doctors from identifying endometriosis in future patients. Attacking the credibility of endometriosis patients has led to delegitimizing them

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[96] Patricia Hill Collins, "Intersectionality and Epistemic Injustice," in *The Routledge Handbook of Epistemic Injustice*, (New York: Routledge, 2017), 121.

[97] Collins, "Intersectionality and Epistemic Injustice," 121.

[98] Collins, "Intersectionality and Epistemic Injustice," 121.

as "epistemic agents," such as the case with discrediting endometriosis patient reports of their symptoms and "eroding their epistemic authority by indirectly attacking their credibility."[99] While the myths of menstrual pain as normal or as a figment of one's imagination are damaging to women and girls for many reasons, in the case study of people living with endometriosis, we start to see how insidious the impact is on reproductive health. When seeking diagnosis for a disease that is not visible on the outside, patients can experience confusion and mistrust in themselves. When their medical provider delegitimizes their experience, it becomes difficult to know how to continue. There is risk involved in gendered approaches to medicine, and as we see through the examples in this chapter, the risk can lead people away from answers and necessary treatments.

If culturally, medical practitioners, friends, and family members begin to shift their perception of women's pain, we might start to see a reduction in the time to diagnosis of endo, and this dissertation participates in creating that shift. As Dr. Seckin shares, menstrual pain is often the first sign of endometriosis.[100] He says:

> The vast majority of my patients had exceedingly painful periods beginning with their very first one, but they didn't say anything to anybody when the pain initially started because they were too embarrassed, they didn't realize the pain was abnormal, or they were shunned by doctors or their loved ones when they did say something.[101]

Therefore, medical practitioners need to start taking reports of painful periods seriously. Nobody wants to have pain, nobody wishes to suffer, so it is unhelpful for medical practitioners to approach their patients with skepticism or gendered notions that a woman's pain is not as severe as she claims. Patients deserve trust and to have more of a role in their diagnosis and treatment. A patients' reports of symptoms should be valued at the same level as a doctor's analysis of what

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[99] Collins, "Intersectionality and Epistemic Injustice," 119.
[100] Seckin, *The Doctor Will See You Now,* 43-44.
[101] Seckin, *The Doctor Will See You Now*, 43.

the presence of such symptoms means. Medicine should aim to be more collaborative, and a shift towards a reciprocal respect might reduce the time to diagnosis for those living with endo.

I have offered deeper insights about some of the most common myths plaguing people living with endometriosis seeking diagnosis. The interviewees addressed the importance of learning that pain is not normal and explicated a tone of remorse when sharing what they can imagine would have been different if someone had listened and taken them seriously sooner. I examined how common myths grounded in gender ideology contribute to human suffering for those living with endo. Throughout this chapter, I argued that the prevailing gendered myths regarding womanhood such as menstrual pain is "normal," that menstrual pain is "all in your head," and that endometriosis should be addressed on the basis of fertility treatment, all are implicit in the ten-year delay in diagnosis of endometriosis for individuals to varying degrees. If women's complaints were heard and evaluated in-depth the first time that they reported them, many women would have spent less time seeking answers and more time focusing on their healing and recovery. The evidence from my interviewees, who have all received an endometriosis diagnosis, prove that the influence of gendered myths is a common factor influencing the delay in endometriosis diagnosis.

As I will discuss in the next chapter, the normalization of pain and dismissal of symptoms as "all in their head" lead many people with endo turn to available literature, which broadly consists of inaccessible medical research or endometriosis self-help texts that provide controversial advice to people with endometriosis. Additionally, due to the impact of living with chronic pain, people with endometriosis start to adopt coping mechanisms to allow them to continue in their condition. The ideology of women's pain impacts those living with endometriosis because they begin to feel responsible in their healing. People with endometriosis adopt strategies to hide their symptoms in the company of others to downplay their illness and “perform wellness,” masking their suffering to comfort those around them.

Chapter 2: "Performing Wellness" and the Rhetoric of Endometriosis Self-Help Literature

When we're in public
And the flare begins,
It registers as a simple
Contortion of expression
Or a hissing of my breath.
The grace of being home is
That I no longer have to waste
Energy on looking okay.
I fall to the ground
Screaming,
No one around
To hear me,
Thankfully.
I'd rather suffer in silence
Than be subjected
To deafening stares.
I feel like I'm in
An abusive relationship
With my body;
No one can see the bruises.[102]

I look down and check the settings on my heating pad: HIGH. Why doesn't it feel like it is doing anything? It is too soon to take more ibuprofen. I tap my foot, trying to distract myself. "Up next, Arline will present," the professor's voice interrupts my thoughts through my headphones. It is the last day of our class, which takes place over Zoom, and everyone is giving a 10-minute presentation of their project. I click to open my PowerPoint and begin to present. "Hello everyone, for those of you who don't know me, my name is Arline Votruba…" just like they describe in movies, it is like I go on autopilot. The words come out, but all I can think about is how the screeching pain in my lower left abdomen feels like it is burning today. The ominous ache of my lower back has not let up for days now. I continue to speak, stopping for deep breaths. The audience won't notice. They will think I am just trying to catch my breath from

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[102] Maggie Bowyer, *When I Bleed: Poems about Endometriosis*, (Greensboro, North Carolina: Margaret Bowyer, 2021), 38.

presenting. I know that I am trying to self-sooth and manage to get through the presentation without grimacing from the pain. Just. Don't. Cry.

Nobody wants to know what I am going through. We are working from home anyways, so I can use my heating pad and nobody can tell. Since we are on Zoom, no one notices that I am wearing the same pajama pants I have every day this week because they do not constrict my bloated stomach. It would be inappropriate to share with the class what it feels like to have severe cramps and ovary pain like this. It hurts terribly. Yet, I feel that there is no sense wasting everyone's time by sharing what I am going through. Besides, I am showing up, so how bad can it really be? If I was *really* sick, I wouldn't be able to present in class.

Smiling when I felt like crying, standing when I felt like lying, I recall how many times I presented myself as happy and healthy while silently suffering. Whether in class, at work, or amongst friends and family, I never wanted to burden anyone with my illness. That is, until I started to do more research and realized that it was important for me to share. My symptoms were real and what I was managing was not typical. Like other people living with endometriosis, I felt fear. Fear of what mix of symptoms I would wake up to each day, afraid of what might happen if I encountered a severe flare up when I was expected to present in class or complete a long shift at work. Yet, I did it anyway. I rarely, if ever, permitted myself to take time off to just rest. Whether I was upright or lying down, the pain would still be present, so what difference did it make? Like so many others navigating the demands of life while simultaneously experiencing debilitating symptoms of endometriosis, I put on a happy face and went about my daily obligations. Rarely sharing my experience, except on occasion with the few people I felt closest to. Even then, often their reactions dismissed my reality. "Oh, when that happens, I just take ibuprofen," or "Have you tried using a heating pad?" *Of course. Those are daily staples.*

The longer I suffered, the more alone I felt. So, I started to do some research. As many living with endometriosis do, I picked up some self-help books to learn more about what I could do. I paid attention and followed their recommendations, but without great success. I could not be the only one who was looking to learn more about endometriosis and found these sources insufficient.

In the previous chapter, I explored how the common dismissal of the symptoms experienced by people with endometriosis leads to a loss of trust in medicine. In *Stop Endometriosis and Pelvic Pain* Dr. Cook claims that, "Because endo is invisible, and because few physicians are specialists in the disease, it is frequently overlooked or misdiagnosed."[103] As a result, many people seek information on their own, turning to self-help literature. In *The Makings of a Modern Epidemic* Kate Seear notes, "Self-help literature is one of the central resources that women draw upon during their experiences with endometriosis."[104] In this chapter, I interrogate how endometriosis patients *perform wellness* as a coping or survival strategy and what that demonstrates about United States cultural beliefs fueled by an entire "wellness" industry. Performing wellness is a term I define in reference to the phenomenon of people acting healthy or pretending to be in a state of well-being while they are simultaneously hiding symptoms of underlying invisible illness. Throughout the chapter, I will argue that the dominant rhetoric of endometriosis self-help texts is implicit in the cultural pressure on people with endometriosis to perform wellness.

This chapter engages with questions like how do endometriosis patients perform well-being? How does self-help culture and the associated expectations shape people with

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[103] Andrew S. Cook, *Stop Endometriosis and Pelvic Pain: What Every Woman and Her Doctor Need to Know*, (Los Gatos, California: Femsana Press, 2012), 13

[104] Kate Seear, *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*, (New York: Routledge, 2014),77

endometriosis's public behaviors? What is the rhetoric of endometriosis self-help texts and how do they impact perceptions of healing with endo? What role might endometriosis self-help texts have in the delayed diagnosis of endometriosis? To answer these questions, first I critique examples from the endometriosis self-help genre and discuss how the texts generate ideas about the role of patients in their healing process. Then, I connect the ideological influence of endometriosis self-help texts to the commonly reported experience of performing wellness. Finally, through engaging with examples from my sample, I connect the role of endometriosis self-help literature to the cultural impact of creating social pressure for people living with endometriosis to perform wellness as a survival tactic.

Although endometriosis is a societal issue, impacting the public in myriad ways, there remains a presentation of endometriosis as an individual problem that one can learn to manage on their own. Endometriosis costs the United States an estimated $119 billion annually for the combined loss of labor attributed to doctor's appointments or taking time off due to pain and other symptoms.[105] In other words, "endometriosis is a public health crisis."[106] The dominant narrative portrays endometriosis as private trouble, not a public issue. However, my work proposes addressing endometriosis as a community issue that impacts our whole population. A collective approach to endometriosis might include better public resources for educating young people about reproductive health symptoms and disease, increased investments in endometriosis research, improved coding of endometriosis for purposes of surgical cost management and insurance reimbursement, the reclassification of endometriosis as a disability, and more progressive sick time policies to provide folks with endometriosis the chance to keep their job

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[105] Lara Parker, *Vagina Problems: Endometriosis, Painful Sex, and Other Taboo Topics*, (New York: St. Martin's Griffin, 2020), 167.
[106] Parker, *Vagina Problems*, 170.

even if they miss time while pursuing diagnosis and treatment for endometriosis. The portrayal of endometriosis as a private issue leads to a strain on public systems by the time it is addressed. Yet, as I will argue in this chapter, the mainstream cultural rhetoric associated with endometriosis continues to position it as an illness that those afflicted should manage and treat individually.

The relationship between self-help and endometriosis warrants additional investigation, as the focus of this chapter extends previous feminist critiques of self-help literature such as that of Maureen Ebben. In "Off the Shelf Salvation: A Feminist Critique of Self-Help," Ebben critiques how self-help discourses reproduce the conventions of medical discourses that pathologize women's natural bodily functions.[107] Ebben critiques self-help texts, which, "posit self-help strategies as virtual cure-alls for the various complicated problems experienced by women."[108] Many self-help texts overstate the potential for one to address complex issues that are often contextual and circumstantial rather than individual, selling readers on ideals of agency and control.

Similarly, researchers such as Sarah Riley et al. contribute to the conversation about self-help in, "The Gendered Nature of Self-Help," in which they critique how "women are often positioned as particularly in need of help to become this ideal individualist self."[109] Throughout the project, Riley et al. emphasize how the genre of self-help focuses on the individual, "at the expense of the social, reducing the possibility of seeking solutions in collective feminist activism."[110] Many social problems such as lack of adequate healthcare or sexism in the

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[107] Maureen Ebben, "Off the Shelf Salvation: A Feminist Critique of Self-Help," (*Women's Studies in Communication* 18, no. 2, 1995), 112.

[108] Ebben, "Off the Shelf Salvation," 111.

[109] Sarah Riley, Adrienne Evans, Emma Anderson, and Martine Robson, "The Gendered Nature of Self-Help," (*Feminism & Psychology* 29, no. 1, 2019), 4.

[110] Riley et al., "The Gendered Nature of Self-Help," 4.

workplace create barriers for women. The foci of self-help as a tool to improve individuals avoids addressing the broader contextual factors such as widespread sexism or limited access to public support that direct women towards self-help in the first place. In closing, Riley et al. note that more research is needed on how, "medical discourses are used, particularly in the contemporary context in which the effects of neoliberal austerity and far-right policies have been disproportionately felt by women."[111] A close read of endometriosis self-help texts expose the underlying gendered messages that present healing as an individualistic endeavor at the expense of critiquing the broader social constraints that contribute to the suffering of the ill.

Self-help scholar Heidi Rimke has written extensively on the topic of self-help and has developed arguments explicitly about the ways in which self-help takes an individualized approach to what were once addressed as public issues. Rimke critiques self-help for its influential hold on citizens and examines how self-help reinscribes social issues as problems to be solved by individuals. In "Governing Citizens Through Self-Help Literature," Rimke explains that the self-help genre often presents, "the self as a unified center of personal agency which can act upon itself, others and the world."[112] Such a conceptualization of 'self' presents the individual as holding an "inner reservoir of power" suggestive of an "intense accountability, responsibility, and sense of obligation that can be enlisted for choices and decisions."[113] Thus, it becomes an individual's responsibility to harness the power within to engage in self-discipline and become the ideal 'self.' As I will discuss throughout the chapter, for those with endometriosis reading endo self-help texts, the promise of healing and relief is offered to those willing to follow the methods prescribed by the author. Rimke argues that self-help acts as a

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[111] Riley et al., "The Gendered Nature of Self-Help," 13.
[112] Heidi Rimke, "Governing Citizens Through Self-Help Literature," (*Cultural Studies*, 14:1, 2000, 10.1080/095023800334986), 64.
[113] Rimke, "Governing Citizens Through Self-Help Literature," 64.

form of governing citizens, through which individual persons' lives are imagined as individualized, thus, "free from state intervention." [114] Rather, self-help offers citizens, "the opportunity for 'choice', for 'autonomous' life plans and the 'freedom' to be the persons they want to be."[115] Rimke concludes, "Above all, we are told, individuals possess the ability to *choose* happiness over unhappiness, success over failure, and even health over illness."[116] Thus, citizens are expected to take problems into their own hands and address them individualistically, and illness has been rhetorically constructed as something one can address on their own. As I will elaborate in this chapter, in the case of endometriosis self-help, readers are promised a choice in their healing, so long as they are willing to follow the outlined lifestyle changes.

More recently, Rimke argues in "Self-help, Therapeutic Industries, and Neoliberalism," that human struggles are more often treated as individual problems in contemporary neoliberal societies.[117] Rimke suggests that "A key aspect of neoliberalized societies is the proliferation of therapeutic industries that produce a self-governing citizenry critical of the self rather than society or authorities."[118] Further, Rimke says, "The role of the self-help movement should not be overlooked in the study of contemporary societies as it forms an integral cultural field, shaping the political, economic, and social rationalities of neoliberalism."[119] Rimke argues that self-help culture has four psychocentric characteristics:

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[114] Rimke, "Governing Citizens Through Self-Help Literature," 72.
[115] Rimke, "Governing Citizens Through Self-Help Literature," 72.
[116] Rimke, "Governing Citizens Through Self-Help Literature," 73.
[117] Heidi Rimke, "Self-Help, Therapeutic Industries, and Neoliberalism" in *The Routledge international handbook of global therapeutic cultures*, (Routledge, 2020), 37.
[118] Rimke, "Self-Help, Therapeutic Industries, and Neoliberalism," 37.
[119] Rimke, "Self-Help, Therapeutic Industries, and Neoliberalism," 47.

> First, it individualizes, depoliticizes, and capitalizes on what are ultimately social problems; second, self-help discourses encourage readers, consumers, users, or subjects to locate ‘flaws’ within themselves rather than deficits within society; third, self-help products generally erase or minimize the importance of social factors in the quality of life; and fourth, self-help discourses tend to distract from wider structural issues of social injustice and social inequality.[120]

The four psychocentric characteristics presented by Rimke are foundational to my approach to an endometriosis self-help case study, through which I investigate how people’s suffering from illness has been capitalized upon and sold back to the ill as ‘flaws’ that they can address individually. Self-help scholars have engaged discussions about how self-help discourses draw from medical discourses, how self-help texts have been constructed through gender, and the ways in which self-help literature represents neoliberal tendencies to project individuals as accountable for what were once public responsibilities of authorities. Building on the research of scholars such as Rimke, Riley et al. and Ebben, this case study extends their arguments through a close reading of one subset of the self-help genre, specifically endometriosis self-help texts.

Endometriosis scholar Kate Seear was the first to engage explicitly with the endometriosis self-help genre in a chapter titled “Standing up to the Beast: On Mystery and Mastery in the Endometriosis Self-Help Literature.” Seear argues that, “Women are positioned as possessing an inherent capacity to overcome endometriosis, but also an obligation – to self and others – to take action.”[121] Her findings indicate that endometriosis self-help texts present endometriosis as something women are, “intrinsically capable of managing and even preventing.”[122] In my critique of endometriosis self-help texts, I verify Seear’s findings that endo self-help texts have the effect of, “Positioning readers as agentive and ultimately capable of acting upon their illness

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[120] Rimke, “Self-Help, Therapeutic Industries, and Neoliberalism,” 47.
[121] Seear, *The Makings of a Modern Epidemic*, 103.
[122] Seear, *The Makings of a Modern Epidemic*, 78.

in important ways, women are encouraged to ‘not despair’.”[123] Seear and I agree that endometriosis self-help provides hope for readers to change their circumstances through following the regimen outlined in the text. I further discuss how the rhetoric of endometriosis self-help texts that present the disease as manageable by the individual contribute to behaviors reported by the interviewees from my sample.

Seear’s work is comprised of a critical examination of eleven endometriosis self-help texts and two chapters from more general women’s health books. In this chapter, I conduct an analysis of additional titles and present alternative conclusions about what endometriosis self-help texts *do*. Furthering Seear’s analysis, I will develop my argument to center the rhetorical structure and uses of endometriosis self-help literature as a genre. I examine how the affect of endometriosis self-help texts are reflected in the data from my interviews with people living with endometriosis who shared accounts of their experiences hiding their symptoms. Additionally, I critique the role of these texts in the mainstream conceptualization of endometriosis, and their influence on people living with endometriosis who adopt an approach of what I call *performing wellness*.

Methodologically, the focus on “self-help” and “wellness” texts emerged because of the research process, guiding me to this analysis. Although I had encountered a couple of self-help texts while seeking answers for my own life with endo, it was not until I began collecting literature about endometriosis for this dissertation that I noticed much of the search results led to texts in the endometriosis self-help genre. I collected as many endometriosis texts as I could. After collecting a wide array of endometriosis self-help texts, all of which were published within the last twenty years, I started to recognize patterns in how the texts marketed themselves and sold the idea of healing to their readers. That is how I arrived at the idea to do a critical reading

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[123] Seear, *The Makings of a Modern Epidemic*, 87.

of how these texts produce people living with endometriosis in relationship to their disease. Through a critical reading of endometriosis self-help texts, I expose their ideological function to further understand the cultural expectations of people living with endometriosis. After providing a critique of endometriosis self-help texts and their influential conceptualization of how people living with endometriosis are expected to participate in the process of healing from their disease, I examine how endometriosis self-help texts contribute to a rhetoric that shapes behaviors reported in my interviews with people living with endo.

Additionally, I conducted one-hour Zoom interviews with eighteen people from the United States who have been diagnosed with endometriosis. I approached the dataset through grounded theory, in which my close review of the data allowed themes to emerge. Drawing from the interview data I collected, I recognized patterns of reports of performing wellness, a process through which people living with endometriosis present themselves as healthy in social contexts because of cultural pressures to mask symptoms when living with invisible chronic illness. The examples of performing wellness that my participants shared further engage the rhetorical patterns I discovered in my analysis of endometriosis self-help texts. I approach this chapter by putting these two sites in conversation with one another, to better establish the relationship of how cultural ideology informs behavior, and therefore, shapes individual experiences. I center the voices of those I interviewed to allow their stories to be central in understanding why cultural rhetoric about endometriosis is implicit in the production of people with endometriosis as responsible for their health, which I emphasize poses a potential hazard to the timely diagnosis of endometriosis.

Endometriosis Self-Help and The Rhetorical Influence of Individualized Healing

The emergence of the self-help genre, an output of the mainstream wellness industry, extends into the realm of medicine and treating specific diseases, such as endometriosis. Small strides of endometriosis awareness have led to the proliferation of a genre of endometriosis self-help literature. Although endometriosis self-help books slightly vary in their approach and content, many of the texts demonstrate a rhetoric through which the person living with endometriosis is charged with manifesting their own well-being. That is, through following the recommendations encompassed in one of these endometriosis self-help books, a person living with endometriosis is promised to find relief and "take back their life." While those suffering from endometriosis might be willing to try anything, the messaging in these texts provides a false sense that the way to find relief from endometriosis is solely the responsibility of the individual. Thus, endometriosis self-help as a genre, charges those living with endometriosis with the task of healing and finding relief on their own.

The growing body of endometriosis self-help literature has led to a variety of approaches, with some hypervigilant on supporting patients to return to their role as workers in the labor force. In *Outsmart Endometriosis: Relieve Your Symptoms and Get Your Career Back on Track* Jessica Drummond emphasizes the importance of finding relief from endometriosis so that you can return to the workforce, noting that "Seventy-five percent of women with endometriosis feel that they have not reached their life potential because of this disease."[124] The implicit message here is that it is important for someone to heal from a debilitating illness in order to return to their profession and participate in the labor force. Drummond creates tension between the reasons for healing in the constant reminder of the relationship between health and career.

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[124] Jessica Drummond, *Outsmart Endometriosis: Relieve Your Symptoms and Get Your Career Back on Track,* (Jackson, Tennessee: Lifestyle Entrepreneurs Press, 2020), 16.

Drummond says, "As you know, reducing your pain, fatigue, and other symptoms is well worth it, even if you never even go back to work. But it's even more important if you desire to have a productive career."[125] Although Drummond might not have intended to hierarchize the reasons for healing, the implications of stating that healing is more important for career-driven individuals places a higher value on someone seeking treatment so that they can tend to the workforce than someone seeking treatment so that they regularly feel healthy and high-functioning. Drummond's recommendations also elicit reminders of the early conceptualization of endometriosis as the "career woman's disease," insinuating that career women are likely those who are afflicted and in need of relief.

Conceptualizing endometriosis as an obstacle that a career-driven person can simply "outsmart" oversimplifies what the process that treatment and recovery for someone with endometriosis might look like. In a chapter titled, "How Can I Hang onto My Job Through Treatment?" Drummond highlights the essential role of work in modern western life and the barriers of living with endo to folks seeking a successful career. Drummond claims, "To work at your highest level as a person with a chronic illness, you have to think of yourself as a 1950s white male executive."[126] Although a good sentiment, Drummond's encouragement for people to get as much help as possible, in practice, is unattainable for many living with endometriosis. Drummond encourages readers to take on the role of a "Mad Men-esque marketing executive"[127] to eliminate or outsource any tasks that do not need to be done specifically by the individual living with endo who needs to heal. This recommendation is problematic in its oversimplification. How can you imagine yourself to be a 1950s White male executive when

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[125] Drummond, *Outsmart Endometriosis*, 17.
[126] Drummond, *Outsmart Endometriosis*, 55.
[127] Drummond, *Outsmart Endometriosis*, 55.

your positionality looks different racially, financially, or culturally? Someone can imagine that they have the privilege of a 1950s White male executive, but the need to survive within the constraints of a racist, sexist, ableist mainstream society will not honor that imagination. Drummond's recommendation is dismissive, excluding a consideration of the real-life situations that her readers might encounter alongside their endometriosis. For many folks living with endometriosis, offloading their tasks like grocery shopping, cooking, caring for elderly family members, or children to someone else is a luxury unimaginable.

For those with the resources to pursue an endometriosis laparoscopic surgery, the preparation and recovery is a weeks-long process, with recovery from surgery taking at least two weeks. Drummond discusses healing in relationship to her recommendations and considers surgery a separate part of the healing process. Drummond suggests that the "intense healing phase" during which one would adopt her recommendations for dietary changes and select therapies lasts "six to twenty-four months, and can be a bit longer depending on if and when you have surgery."[128] The long time period required to heal, coupled with Drummond's suggestions that taking that time "off" from responsibilities, represents a self-help model unattainable to the average person navigating endometriosis. While work might be one of many motivational factors influencing why someone pursues endometriosis treatment, it is important to recognize that the fundamental reason to treat any disease is to remove the risks and symptoms associated with the disease from the person's lived experience. Additionally, for most, work is not a negotiable part of life, but rather a necessity for survival due to the high cost of living.

Another endometriosis self-help text titled, *Endometriosis: A Woman's Guide to Beating Endo, 7 Steps to Dealing with Endometriosis Naturally*, by Porsha Keys uses the rhetoric of

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[128] Drummond, *Outsmart Endometriosis*, 56.

"beating" endo to entice readers. Keys is an accountant, but after being diagnosed with endometriosis, she wrote a self-help text directed towards people suffering from endometriosis. Keys' *Endometriosis* is advertised to help readers discover, "Pain relief options that skip the surgeries and prescriptions to help you manage endo discomfort through natural remedies."[129] Self-help guides such as Keys' are available through quick internet searches and are relatively affordable when compared to the out-of-pocket expense often associated with seeing an endometriosis specialist, which is why many people with endometriosis would rely on such a text to learn how to treat the disease without surgery. This said, when Keys shares her story in the last section of the book, she notes that she underwent a laparoscopy and had endometrial tissue removed, thus contradicting the ethos of the text. Throughout the work, Keys perpetuates ideas that endometriosis has no cure, which connotes that it remains untreatable or unmanageable. Yet, she had surgery while promising solutions that bypass surgical intervention. Keys' presents her text in such a way that readers might deduce that if they follow the recommended prescription of "seven steps" they can "beat endo" "naturally."

While it remains important that people who have gone through their own endometriosis journey share their stories, I maintain that the rhetorical impact of Keys' work misleads people with endometriosis, overstating the potential results of the recommended steps. The messaging to folks searching for answers when they purchase a "guide" promising "seven steps" to "beat" endometriosis is misleading. As Seear says in her chapter engaging endometriosis self-help texts:

> Self-help authors do not simply seek to increase women's access to information about endometriosis, however. They aim to also motivate them to take action, propagating the idea that women can manage the disease and their symptoms, or even prevent it from recurring or proliferating.[130]

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[129] Porsha Keys, *Endometriosis: A Woman's Guide to Beating Endo*, (North Haven, CT: Porsha Keys Author, 2021), (Back cover).
[130] Seear, *The Makings of a Modern Epidemic*, 86.

I notice in my review of endo self-help literature that like Seear's observations, authors of endo self-help literature, such as Keys, capitalize on the vulnerability of people seeking support for their healing while making empty promises. As the remaining examples will show, I am weary of the general misconceptions that endometriosis self-help texts reify. Keys' is not the only endometriosis self-help text capitalizing on the concept of "beating" endometriosis. Creating a false sense of hope that one can recover individually, endometriosis self-help texts deepen the rhetorical messaging that one can 'beat' endo on their own.

In *Beating Endo: How to Reclaim Your Life from Endometriosis*, Iris Kerin Orbuch and Amy Stein, a gynecologist and physical therapist respectively, claim to have:

> …devised a multifaceted and integrated approach that beats the disease known as endometriosis, an approach that gets past precisely what was afflicting these patients. The approach does not *cure* endometriosis; there is not yet a known cure. But it does empower those who have the disease to keep it from taking over their lives so they can reclaim the quality of life they want and deserve.[131]

The use of the title "*Beating Endo*" generates hope and confidence in those seeking information that there is, in fact, a cure and approach to full relief from endometriosis. Yet, once cracking open the text and reading just a few paragraphs, readers are told that there is not a cure to endo. In fact, Orbuch and Stein also make a passing comment in the introduction that surgery is not a cure for endometriosis.[132] Throughout the text, there is a tension between the authors' push for a multimodal strategy for treating endometriosis, and their resistance to claim surgery as a cure. Later in the introduction, Orbuch and Stein note that the multifaceted approach to treatment they devised does include, "the excision surgery that is the sole known method for *removing* endometriosis from the body," (XXIX). What remains perplexing is why the authors of

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[131] Iris Kerin Orbuch and Amy Stein, *Beating Endo: How to Reclaim Your Life From* Endometriosis, (New York: Harper Wave, 2019), XXI.

[132] Orbuch et al., *Beating Endo*, XIV.

endometriosis self-help texts present their approach as substantially different from other advice about treating endometriosis, yet, they still claim that excision surgery is the gold standard approach to treating endometriosis as a part of their multi-layered recommendations. It is important to note that whether or not endometriosis deep excision surgery is a cure remains up for debate. Specialists, like Dr. Tamer Seckin suggest that if treated early enough, a successful endometriosis deep excision surgery can remove all the disease and relieve patients' endometriosis symptoms.[133] Thus, Orbuch and Stein's work does not meaningfully offer an alternative route for "beating endo." Instead, *Beating Endo* reifies the work of other leading specialists in the field through repackaging endometriosis treatments through a self-help lens, advertising the text as a key to "reclaiming your life from endometriosis."

An exemplar of the approach taken across the endometriosis self-help genre, buried in the chapters of *Beating Endo*, which recommend alternative treatments to manage pain, is the counterargument that surgical excision is the only means to remove the disease from one's body. Throughout the text, Orbuch and Stein recommend people with endometriosis modify their lifestyle through making changes to daily nutrition, adjusting state of mind, and using "yoga as therapy."[134] However, Orbuch and Stein note in the eleventh chapter, "None of the treatments you may be trying make the endo go away either."[135] Over 200 pages into the text promising an approach to "beat" endometriosis, the authors acknowledge that relief from endometriosis symptoms through pain management techniques such as lifestyle changes does not remove the endometriosis from your body, and in fact, endometriosis might continue to grow while you

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[133] Tamer Seckin, *The Doctor Will See You Now: Recognizing and Treating Endometriosis*. (Nashville, Tennessee: Turner, 2016), 174.

[134] Orbuch et al., *Beating Endo*, 199.

[135] Orbuch et al., *Beating Endo*, 207.

manage and treat symptoms.[136] Orbuch and Stein add, "What does actually eradicate the endo in your body is surgical excision—that is, cutting it out of you. That surgery is the cornerstone of beating endo."[137] While it has been documented that other strategies and holistic measures to improve one's health are supportive alternatives for endometriosis pain management and recovery,[138] the pitfall of the self-help genre is misleading readers about the role of deep excision as the basis of their recovery. Readers expect to learn something new and gain insights about "beating" the disease through mixed-methods, which leads readers to believe that the book will offer alternatives to surgery. Encouraged to try physical therapy, nutrition, mindfulness, and adjusting their environment, ultimately the authors point readers towards excision surgery. Perhaps the multi-faceted approach does lead to better outcomes, but paying attention to cultivating healthy habits with nutrition, mindfulness, and their environment are supportive of anyone's health. Unfortunately for the new patient who is trying to get answers, following the chapters like a step-by-step protocol will eventually lead to the understanding that surgery is the way to rid them of the disease.

The misleading references to surgical options are not limited to authors burying the need for surgery deep in their pages. Other endo self-help texts include deceptive information about what types of surgery are most often performed to treat endometriosis and the expected results of those interventions. *How to Heal Endometriosis Naturally: A Holistic Approach to Recognizing and Treating Endometriosis* by Barton Press, acquired on Amazon is another self-help text designed to teach people with endometriosis how to heal and treat themselves "naturally." Uniquely, *How to Heal Endometriosis Naturally*, lists no primary author, simply stating "By

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[136] Orbuch et al., *Beating Endo*, 207.
[137] Orbuch et al., *Beating Endo*, 208.
[138] Seckin, *The Doctor Will See You Now*, 131; Cook, *Stop Endometriosis and Pelvic Pain*, 140.

Barton Press” on the title page. In addition to the questionable ethos due to ambiguous authorship, there are major omissions that discredit the text, once more placing the burden of executing a treatment plan solely on the patient. In the section titled “‘Traditional Treatment’” [quotation marks in original text] Barton Press includes a section on surgery that jumps to conclusions without offering accurate information about the most common endometriosis surgical options. Within the section “Surgery,” Barton Press claims that surgery is,”…by far the most drastic and permanent of the ones [modern treatments] mentioned,” continuing, “Total hysterectomies are the second most common surgery among women in the United States.”[139] The jump from surgery to hysterectomy presents readers with the idea that the only modern surgery available for people with endometriosis is a hysterectomy. Omitting any mention of the most common endometriosis surgeries, laparoscopic ablation and laparoscopic deep excision, which are themselves distinct treatments, creates misunderstandings for readers. The section goes on to discuss the risks of hysterectomy and noting that a hysterectomy is not a cure for endometriosis since tissue can be left behind, which is a critical truth, but the section on surgery never discusses ablation or deep excision.

Deep excision is the gold standard of endometriosis treatment,[140] though Barton Press positions itself as opposed to “traditional treatment,” the text makes no note of the most common surgical options for treating endo. Presenting the reader with recommendations for diet, exercise, and lifestyle changes, Barton Press echoes other self-help texts stating, “Knowing that there is no official cure for endometriosis can feel crippling, but it does not have to.”[141] With advances in deep excision treatment, it is damaging to perpetuate the idea that endometriosis is untreatable or

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[139] Barton Press, *How to Heal Endometriosis Naturally: A Holistic Approach to Recognizing and Treating Endometriosis*, (Milton Keynes, UK: Barton Press, 2021), 22.
[140] Seckin, *The Doctor Will See You Now*, 173.
[141] Barton Press, *How to Heal Endometriosis Naturally*, 25.

has no cure. Rather, the best available treatment is highly inaccessible to the people who need it most. However, a text such as *How to Heal Endometriosis Naturally* available for purchase through mainstream platforms such as Amazon for as little as $14.07 may be more accessible for people with endometriosis trying to figure out next steps towards their healing on a budget.

While examples such as this one from Barton Press demonstrate the most wavering of self-help guidance, some endometriosis self-help texts are firmly grounded in research, or include a nuanced approach to informing readers of the options- even when the matter-of-fact recommendations remain inaccessible to most. In *Living Well with Endometriosis: What Your Doctor Doesn't Tell You… That You Need to Know*, Kerry-Ann Morris provides readers with researched information on topics ranging from understanding endometriosis to treatment options, thinking holistically, and creating an endometriosis repair plan. In the chapter titled, "Create a Dynamic Treatment Team," Morris advocates for, "A multidisciplinary approach," which, "will involve several medical specialists and complementary and alternative medicine practitioners- in essence, a team approach."[142] While the recommendation is effective and does dramatically shift away from placing the burden of healing strictly on the individual, it glosses over the availability of such resources to the average patient. When referring to a team approach, Morris recommends someone with endometriosis put together a team, not limited to, family medical practitioners, general practitioners, gynecologists, reproductive endocrinologists, allergists/immunologists, pain management specialists, gastroenterologists, surgeons, nutritionists, registered nurses, traditional Chinese medicine practitioners, herbalists, and of course, an endometriosis specialist. Although this strategy would lead to improved outcomes for anyone with endometriosis, it would

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[142] Kerry-Ann Morris, *Living Well with Endometriosis: What Your Doctor Doesn't Tell You… That You Need to Know*, (New York: HarperCollins, 2006), 292.

be difficult to successfully navigate without access to healthcare, funding, or time to pursue all the necessary appointments. For many people with endometriosis, lack of access to adequate medical care and support services such as access to childcare or paid time off pose substantial barriers to their search for diagnosis. Thus, while self-help texts might recommend establishing a multi-person team, or as discussed earlier in the Drummond piece, to take time off from work to heal, the classist implications of such recommendations dismiss people living with endometriosis of a lower socioeconomic status from the audience of folks who can take these actions towards their care.

The "do it yourself" rhetoric touted in endometriosis self-help books echoes and fuels the pressure on folks suffering with endometriosis to take responsibility for their illness and perform wellness as a means of agency. Endometriosis self-help literature exposes how patient guides shift the responsibility of managing illness onto readers and often provide readers with false hope that following certain steps can lead to relief. I acknowledge that many endo self-help texts provide helpful information to readers that can support coping or pain management strategies. However, I critique the step-by-step approaches that capitalize on the vulnerability of endometriosis patients trying to heal. Feigning that by completing the recommended steps provided in a text that one might "treat," "outsmart," or "heal" their endometriosis on their own, these texts produce the person with endometriosis as responsible for their illness.

The endometriosis self-help genre is representative of broader ideologies about the role of patients as agents in their own healing. The form of agency produced through endometriosis self-help texts is pernicious because it positions patients as capable of reaching healthy outcomes on their own. Further, endometriosis self-help books endorse claims that patients are responsible for their healing. The self-help promoted agency ends up leading to the destabilization of their individual credibility because the individual learns to mask their symptoms and hide their experience. Internalizing a self-help logic that following certain steps can help one heal from endometriosis on their own can lead to a mentality that hinders one's acceptance of the need for outside intervention. Since there is a cultural pressure to appear healthy, especially when no signifiers of illness are visible to onlookers, people living with endometriosis adopt methods for managing their illness in silence and solitude, hiding their symptoms publicly. In the following section, I engage with how the phenomenon of performing wellness is a response to the broader rhetorical messaging coalesced within endometriosis self-help texts, which are factors that may contribute to the delayed diagnosis of endometriosis.

The endometriosis self-help texts I critique espouse rhetoric that frames endometriosis as an individual problem rather than a societal issue. Placing the pressure on folks struggling with endometriosis symptoms to heal on their own or lead their own care team insinuates that folks can achieve relief by taking responsibility, a complex message for people living with a chronic illness. Aligned with other scholarly criticism of endometriosis self-help, my analysis confirms Seear's statement that, "In self-help literature, the central resource in mastering disease is not the doctor, nor the expert authors of the books: it is the sufferers themselves."[143] The burden to engage in self-help and self-healing might develop a sense, for some readers, that if they follow the recommendations and do not feel better, they (not the treatment) are failing. Because of the cultural expectations for ill-persons to become agents in their own healing, those suffering from endometriosis often appear that they are "handling it" while, they are living a plurality of experiences.

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[143] Seear, *The Makings of a Modern Epidemic*, 103.

Performing Wellness: Publicly Masking Endometriosis Symptoms

The cultural pressure of managing health individually, such as the onus on people with endo to heal on their own reified through the rhetoric of endometriosis self-help texts, creates expectations for sick persons living with invisible chronic illness to present themselves as feeling healthy to comfort others in social situations. In Seear's work, she claims that endometriosis self-help texts exemplify the pressure for women to manage their emotions, "…whereby women are expected to perform themselves in particular ways and to put the needs of others first, presumably based on the assumption that this will benefit others."[144] Building on her work, and through reflecting on the many stories shared by my interviewees, I conceptualize the phenomenon of acting well in front of people while managing symptoms of invisible illness as performing wellness. Performing wellness is an enactment of cultural expectations, through which one presents themself as healthy in the presence of others. In the instance of endometriosis, performing wellness refers to presenting behaviors aligned with well-being to conform to gendered expectations that menstruation is an unspeakable private event.

Many of the people with endometriosis that I interviewed shared examples of performing wellness. I argue that the cultural expectations perpetuated through endometriosis self-help literature contribute to the expectation that people are responsible in their own healing. Further, the cultural messaging is that if someone does not appear visibly ill, they should behave as though they are not ill for the comfort of others, friends, family, coworkers, and even doctors. Since there is cultural pressure to, as Grace, a 30-year-old woman from Illinois explained it "be on" in many spaces, people with endometriosis often avoid sharing their symptoms. Grace

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[144] Seear, *The Makings of a Modern Epidemic*, 92.

added, “I don't tell people I'm in pain.” Due to the pressure to live healthily, many people living with endometriosis adopt coping mechanisms of code-switching, in which they behave differently in settings amongst different groups of people. Self-censoring their expression of symptoms amongst different company, people with endometriosis code-switch each time they hold back from vocalizing or physically indicating that they are experiencing uncomfortable or debilitating symptoms to avoid inconveniencing others. This might look like standing up straight when doing so is physically agonizing or remaining quiet when one would be whimpering from pain if they were alone. People with endometriosis perform wellness to survive, trying to maintain their cultural value by hiding their lived experience. In the following analysis, I highlight examples from my interviews in which people with endometriosis share how they have performed wellness.

The cultural norms pressing someone with endo to perform wellness as an adaptation to survive is tied into social expectations for women to remain silent about their complaints, specifically when those grievances are associated with menstrual health. The message is that it remains culturally inappropriate for women to talk about their periods publicly, so instead people with endometriosis pretend that they are feeling okay to avoid controversial responses by outsiders. Some of the common threads contextualizing the examples of performing wellness by the interviewees living with endometriosis include self-censorship and hiding their symptoms. For example, some interviewees report that they refrained from talking about their symptoms with people. Charlie, a 28-year-old woman from Vermont shares, “I was open to talking about anything, but I just never shared with people, my discomfort or my symptoms.” Hiding her symptoms from people in her life was a way to mitigate the taboos associated with discussing menstrual health and sickness. Similarly, Kylie, a 41-year-old woman from North Carolina shares the contradiction between how difficult it is to manage life with endometriosis alongside the pressure to be okay:

> I am debilitated from doing anything else during that time. Yeah, but it's also weird because it's like this cultural expectation that you grin and bear it when you're having your periods. So, it's just that like, the mental gym. It's exhausting. Just mentally the like, it’s just like, ‘Okay, I gotta go face the world.’ Like, and pretend like nothing's wrong, when in fact, I'm so miserable.

Kylie expresses the cultural knowledge that she must act well because it is expected of her. Although she feels unable to do regular daily activities during her menstrual cycle, there remains pressure to perform wellness and “pretend” if she intends to go on existing in this world with some cultural value. Kylie shares how her misery is something to be dealt with in private even though she is debilitated. The pressures to be well and execute daily obligations while suffering debilitating symptoms is an undue pressure on folks living with endometriosis. Denying her symptoms by “facing the world” while managing the exhaustion of navigating the mental and physical burden of her illness, Kylie’s experience allows us to understand the impact of cultural pressure to be well on folks living with endo. Kylie’s experience demonstrates how people living with endometriosis train themselves to self-censor in such a way that it becomes habit, so it is unlikely that they feel comfortable sharing their experiences with others. The practice of hiding their illness becomes embedded in their lived experience in such a way that I anticipate contributes to their delayed diagnosis, because the story they tell themselves is that what they are experiencing is not that bad. Their denial of the symptoms in practice through code-switching amongst other people to hide their illness might create an obstacle for people with endometriosis in the context of speaking to their doctors about their illness, because they have become accustomed to downplaying their symptoms.

Interviewees shared their awareness that the pressure to perform wellness is taught through social and cultural norms. Connie, a 26-year-old woman from Washington state expressed frustration saying, “So I think it's just like society. Why is that how they have conditioned us to just be like, ‘Oh, it's okay.’” Frustrated with the pressure in society to act fine, Connie shared a dialogue, grappling with the back and forth between how women are expected to just “downplay” their symptoms and “just deal with it,” because people do not want to confront why people who do not look sick in culturally expected ways are suffering. The invisibility of endometriosis to outsiders cause a perception that the individual is healthy. However, there can be many symptoms challenging the person daily and if one were able to look inside of the person, they would be able to visualize the endometrial growths contributing to the person’s suffering. The invisibility of endometriosis creates a false sense to outsiders looking in that it is not that bad or that perhaps the disease is just a “bad period.” Since patriarchal expectations of women insist that menstruation remain a private and hidden event, the mention of menstruation challenges the status quo. Thus, reports of painful menstrual-related symptoms are met with dismissal by friends, family, and doctors alike who assume that since the individual does not look sick, they are not in fact suffering. The invisibility of the illness is at odds with the common approach by people with endometriosis to perform wellness because hiding their symptoms substantiate the idea that they are not sick.

Many others from my sample shared instances in which they behaved as though nothing is wrong, or intentionally omitted discussions of their symptoms when in the company of others, just to avoid disbelief or negative judgement from those around them. Valerie, a 31-year-old woman from California shares, “Yes, I'd always sit there and fake my symptoms, or, you know, hide them or lie about them. Just so I can have a good time. And people wouldn't question me and, or get tired of me." The cultural expectations that health is something someone should manage in private results in many examples through which people with endo self-censor, perform wellness, and attend to the needs of others around them so that they do not make anyone feel uncomfortable. Zoe, a 34-year-old woman from Pennsylvania, explains the pressure to participate in daily obligations and hide her experiences:

> But it wasn't, it wasn't a situation where I was like, I wasn't saying to people, like 'I don't feel good and this is why.' I was definitely, I was definitely doing whatever I could, on my end, to manage my behind-the-scenes stuff, sort of show up where I was expected to show up.

Zoe explains how she would manage the symptoms of endometriosis in private. Showing up where she needed to be, Zoe hid that she was feeling unwell from the people around her, doing what she could to disguise her illness. Like Valerie, Zoe tried to keep her experiences from others to avoid their judgement. Both Valerie and Zoe shared how they self-censored their symptoms from people around them as a strategy to avoid becoming a burden to others.

To further demonstrate the impact of performing wellness, Kylie, the woman mentioned earlier from North Carolina who explained how debilitating endometriosis is, shared how the process often looks like showing up and acting fine in one context, to unravel and be herself as soon as she is in private. An example of code-switching, Kylie shared, "Zoom has actually been great because I can like, 'Okay, hi, everyone.' And then like, just go lay down right afterwards. Because, like, it'd just be so, so exhausting." Sharing how the shift to online meetings during the Covid-19 pandemic has had a positive impact on hiding the experience of living with an invisible chronic illness demonstrates the lengths that people living with endometriosis often go to avoid showing others their illness. In instances as visceral as this, it becomes evident how much pressure there is on people with endometriosis to compartmentalize their experiences. Navigating the demands of life, having to pretend to feel well in the presence of others, while simultaneously suffering from symptoms can lead to mixed feelings for people living with endometriosis.

Since endometriosis can only be visualized through laparoscopic procedures, many people with endometriosis do not "look sick" by cultural standards. Tanya, a 37-year-old woman from Mississippi shares what it feels like navigating the pressure to hide her illness. Tanya shared:

> People don't see endometriosis. Like, you can't look at me and know that I have endometriosis. So, a lot of times, I just push through because, I'm not one that does well with sympathy for starters. So, I don't want people feeling sorry for me. But I also, you know, don't want the attention of, 'Oh, she's sick all the time.' Or this, you know, that and the other so I just kind of push through a lot of times and especially with work, family functions, sometimes I'll push through things, you know, just to not be that sick person all the time.

Adopting the strategy to perform wellness means that although someone might be struggling with physical symptoms associated with endometriosis, they act fine in social or public contexts. Tanya shares how performing wellness is not just a strategy used at work, but that she also hides symptoms from her family to avoid being perceived as always sick. To mitigate an image of being ill, people adapt to perform wellness by standing up straight, smiling, and carrying on as though nothing is going on internally. Meanwhile, below the surface they might be struggling to show up and remain calm, which can place a wedge between the person who is suffering and their loved ones, because they are not sharing their experiences. Unfortunately, the hidden nature of endometriosis can feel quite isolating to some.

In another example from my interviews, Lilly, a 33-year-old woman from Texas shared that living with endometriosis is:

> Like having a monkey on your back, but no one else can see it. And you don't tell anybody else about the monkey, because they can't see it and think you’re crazy, or that you're exaggerating. So, sometimes it can feel really lonely, and frustrating. And then other times, it's like a cross to bear type situation. And also, I sometimes feel like… isolated.

When people with invisible illness, such as endometriosis, perform wellness, it can result in feelings of loneliness and isolation. Since there is a culturally taught expectation to face the illness alone, in silence, there is pressure to act fine when someone with endometriosis might be having a hard time managing their symptoms. The expectation to appear fine to socially comfort others is ostracizing, leaving people with endo feeling stuck in solitude, and contributes to a silencing of people ill with reproductive diseases. Moreover, the cultural pressure to hide menstruation and to not discuss it publicly can be weaponized against people with endometriosis when they do decide to speak out about the illness. The effect of the tension between living one experience and presenting oneself as living an alternative reality is that people feel very lonely in their situation.

The invisibility of endometriosis deepens the pressure for folks to present themselves as healthy individuals. Even medical practitioners, such as Sophia, a 37-year-old woman from California, shares that her work as an occupational therapist has informed how she sees her own experiences with endometriosis:

> I think because I'm an occupational therapist, and I worked in skilled nursing with people, you know, end of life or, you know, traumatic experiences young life, I've always felt like, ‘Man, I can get up and I can get up out of bed and walk. I don't have to wear a diaper. I can feed myself.’ Like, if you can do that, you should never feel bad about yourself. And you should show up because there's somebody who can't even do that. And so, I think for so long, like, you're seeing like, you know, the whole normal thing, my perspective of a normal human existence was anything where a person was breathing in that range, and everybody's like, ‘Oh my God, you're acting like you're old and dying already.’ And I'm like, ‘Well, I feel old and like, I'm dying already inside.’ But I've also been around people that have. That's where they are at in their life. And so, I feel like I minimize my own experience because I compare it to a different range outside of a normal range.

Although I continue to discuss the pressure for folks to perform wellness as a social pressure to act well if their illness is not visible, the above quote from Sophia also deepens the cultural expectations of who is expected to be sick. Referring to people who are old and dying as those that are expected to display outward signs of sickness points to the way younger folks, such as those of reproductive age, are not seen as meeting the prerequisite for experiencing illness. Those afflicted by endometriosis do not meet cultural expectations of what illness "looks like" and thus, people with endometriosis tend to perform wellness to conform to social and cultural expectations of well-being. Since they are often dismissed when sharing their symptoms or are fearful of sharing their symptoms because of the judgement they might receive, people with endometriosis often, as Sophia shares above, have difficulty accepting that they are themselves sick. Since the pressure to get out of bed and participate leads many with endometriosis to push themselves to continue to meet their daily obligations, it can be difficult for those with endo to recognize themselves as ill. That is, the cultural ideology of what illness looks like is so widely taught that people who have difficulty navigating life with debilitating symptoms can still get stuck in a cycle of minimizing their experiences and denying themselves access to claiming that they are sick.

Performing wellness can be personal and trickle into social relationships, such as between someone with endometriosis and their partner. Grace, mentioned earlier, explained that "Sometimes with my boyfriend, he's like, 'Are you okay? Do you want to go out?' and I really want to go out but I'm really in pain…So, there's often times where I just don't talk about it, I just deal." Of course, there can be tension building when within a romantic partnership, someone suffers symptoms that they do not share openly. Whether the person managing endometriosis symptoms in silence is doing it to comfort their partner or avoid receiving pity from others, the lack of communication can result in distance between the couple, leaving the person with endometriosis feeling isolated.

The folks living with endometriosis I interviewed provided examples within a variety of social encounters through which they felt pressure to perform wellness. Mia, a 38-year-old woman from Illinois discussed her years of participation in a book club. Mia said that one day, she finally shared a post online about her experience with endometriosis and said:

> One of the women from my book club, actually, in response to one of the posts that I made on Facebook, her comment back was like, 'Wow, I had no idea. So you've been suffering in silence all these years.' I've been in this book club for years. And, and it was like, yeah, like, wow, I guess I fooled her. You know, 'cause like, yeah, like, there's been a ton of pain, like, I guess they really didn't know, you know?

Participants like Mia shared how through social media, they can censor who has access to information about their illness. Mia shared how she "fooled" the person from her book club because when she went to meetings, she would perform wellness so nobody detected what was going on beneath the surface. As I discussed earlier, code-switching occurs when someone with endometriosis presents one reality in the presence of others but experiences an alternative reality once they are alone. Navigating different spaces through conflicting approaches demonstrates the lengths that people with endometriosis go to mask their illness. For Mia, showing up to book club was a space where performing wellness provided a mechanism for misleading the other members to believe that nothing was wrong. However, through her engagement online, Mia shared information about her experiences with endometriosis, which exposed the contradictions between her behavior at book club and her experiences with endometriosis to unsuspecting members.

Additionally, many folks throughout my interviews shared examples of performing wellness within work contexts. For example, Raya, a 29-year-old woman from California said:

> I mean, there'd be times where I'm like, in a meeting and like, I'm in so much pain, but I'm making jokes and I'm laughing. I've always been that person that like, doesn't want to burden other people with my own pain or issues. And so, you know, I'm always, you know, in a good mood and smiling and part of it is that like, I'm gonna be in pain, whether I'm making jokes and laughing or if I like sitting and sulking, like either way I'm gonna be in pain. So like, I'm like, why not, like try to have fun but a part of it also is for other people's comfort for sure. Like even, like, on like Instagram. Like if I want to post about like my endometriosis or the pain I'm in like, I almost feel like no one wants to see that like, that's just gonna annoy people like that's not what this was for like I started like a little separate Instagram just for like my endometriosis stuff because I was like I don't want to be on about it all the time. But so, yeah, definitely a good amount of masking.

The above example from Raya displays how engrained cultural expectations of health and wellness create conditions in which someone living with endometriosis can have two contradictory experiences simultaneously. That is, performing the external behavior of laughing along in a social context, while concurrently navigating the symptoms associated with illness. A visceral example of performing wellness, the emotional and physical toll of hiding one’s symptoms from others causes contradictions within one’s sense of identity. Compartmentalizing life with endometriosis as a separate experience, hiding symptoms at work, and showing up to interactions with others are a result of the pressure placed on those living with endometriosis to show up and pretend that they feel fine to avoid creating discomfort for others.

Raya elaborates, reporting how pressure to perform wellness in work contexts has led her to pretend that she felt fine while managing symptoms in public:

> People just downplay the pain. Like, ‘Oh, you're fine. Suck it up.’ No, like, if I can transfer this pain to you, you can just understand for just one second, you would probably understand how bad it is for me is trying to stand here and do my job when my body is attacking itself. But it feels like it's just like they're going at it, punching -stabbing each other. And you're just like, ‘Okay, take a deep breath, you're fine.’ Like, you know, and you're trying to not show anybody else.

The pressure to hide illness, even an invisible one, from colleagues at work speaks to the expectations to manage health on your own. It also demonstrates the cultural value ascribed to showing up to your workplace and being productive. The cultural messaging that people should go to work and sustain good health presses many living with endometriosis to code-switch, putting on their workplace persona and hiding their illness at all costs. Although in their daily life they navigate painful or frustrating symptoms, they are expected to keep that information to themselves and hide it from their workplace. Since endometriosis is so deeply intwined with menstruation, people with endo often try to participate at work and avoid mentioning their symptoms because they do not wish to reproduce stereotypes that women in the workplace will not be able to keep up because of their periods. Instead, there is even more of a sense that one must perform to establish a good reputation at work.

Sometimes, someone's work context deepens the gendered expectations that shape how a person is expected act. Connie explains how her role as a woman in the army, which is predominantly comprised of men, has led to additional challenges with navigating their cultural role and expectations with their lived experience dealing with endometriosis:

> Like, especially now in the army, like, I have to do it [mask symptoms] a lot. Like, even when I feel so shitty, and I'm like, I can… I can call in, but they're gonna be like, 'Why are you calling in? Oh, it's just your period.' And I feel like… whatever. So I got to work, pretending everything's fine. I do.

Connie expressed the pressure to avoid mentioning symptoms and experiences related to menstruation at work. She highlights how if she needs time off because of her symptoms, she would be questioned and dismissed for exaggerating and that speaking about menstruation would be met negatively, reifying stereotypes about women and their menstruation. As a result, she continues to partake on days that she feels sick, acting like everything is okay, because the cultural response by her supervisor or colleagues is seemingly worse than the pain of performing wellness at work all day. Due to gendered myths that lead folks to assume that periods are painful or that women who complain about their periods are making excuses, Connie must overcompensate and hide her symptoms at work to avoid being dismissed. The enactment of wellness to protect oneself from gendered discrimination is damaging and an undue burden on women with endometriosis navigating the disease alongside work and life obligations.

Many of the participants noted examples of performing wellness in the context of work. Often, the pressure to be well is enough to push folks living with endometriosis into situations where they are forced to act okay to avoid discomfort with their peers. Brooke, a 27-year-old woman from Massachusetts shared:

> Like, I think it was three weeks ago, I mentioned that I didn't go into work that Monday, but I went on Tuesday. I was in so much GD pain, I wish I could have been at home, I was like, I was out of it, couldn't stand. I could barely go to the bathroom. I wasn't hungry. I felt nauseous. But I had to, because of the resentment that I'm feeling myself. For my coworkers, I had to kind of mask and try to act like everything's okay.

Brooke explains how she felt pressure to navigate the workplace while enduring symptoms so severe that she could not stand because of internal feelings of conflict resulting from cultural expectations. Since societally people are expected to attend work, especially if their illness is invisible to the outsider looking in, it breeds internalized feelings that the person suffering from invisible symptoms is not doing enough or trying hard enough, rather that they are making excuses. Due to the pressure to conform to expectations of showing up no matter what, the interviewee explains that she would pretend that she was well and uses the term “mask” to explain how she presented another version of herself, as if hiding behind a costume. Showing up and acting fine while she was unable to function at a basic level, the interviewee’s example indicates the severity of the issue. Do we want people going to work who are on the brink of collapse? Is it appropriate to expect someone who cannot eat or use the bathroom to perform a job? The many examples shared by interviewees amplify the pressure within United States culture to prioritize work over everything else. The examples show how performing wellness for the sake of your career is a culturally more acceptable behavior than calling out sick for a disease related to menstrual health. Since there can be months or years of time lapsed, during which the person living with endometriosis has convincingly masked their symptoms, others might be surprised if the person starts to share what their experience has been. Additionally, the practice of performing wellness becomes instinctual, and those living with endometriosis might not notice that they are actively performing wellness in many contexts. Perhaps, their adaptation to perform wellness becomes so commonplace, that when facing doctors who ask how they have been feeling, they do not have the words to describe their experiences or lack any inclination to report their symptoms. Alternatively, if they do share with doctors, perhaps the fact that they have managed to continue going to work and navigating their obligations creates misconceptions that they are not suffering. Either way, it is logical to deduce that the very act of performing wellness is a cultural factor contributing to the delayed diagnosis of endometriosis.

The pressure of masking symptoms comes at a cost to individuals that can be damaging to their health because it prolongs diagnosis and subsequent treatment. Peyton, a 23-year-old from Washington, expressed that, “When I would mask my symptoms, it would quite literally take all of my mental energy to not let it show.” When one is already navigating a combination of debilitating symptoms, it is an unreasonable societal charge to then burden them with pretending to be fine in the service of others. Peyton added:

> I would be constantly in pain, which meant that I was constantly masking my symptoms. When in reality, someone was talking to me I'd be like, ‘Yeah, okay.’ But what I was trying to do was not whimper, not curl in on myself not succumb to that. Dark spots in my vision. I would just be doing everything I could be like, miss. Yeah, I hear you. Okay, yeah. Haha, funny funny. But like literally trying not to collapse.

Listening to endometriosis patients’ descriptions like this better contextualizes the strain it puts on the individual to perform wellness. The dichotomy between what they were feeling physically and their social behavior is a contradiction that only the person navigating dual realities is aware of in the moment. The cognitive dissonance navigated by people living with endometriosis might influence their delayed diagnosis because they do not practice reporting symptoms to others. As endometriosis specialist Dr. Cook observes of his patients with endometriosis, “They’ve been through so much unnecessary pain, yet they’re afraid to talk straight about their problems because people have disbelieved them so often.”[145] They do not have the vocabulary or practice of expressing how they feel to people outside of themselves. The weight of the symptoms they experience in contrast to the pressure to behave within the social contract indicates one potential factor influencing the delayed diagnosis of endometriosis. Those debilitated by endometriosis are expected, culturally, to hide that they are debilitated by the illness. They are expected to show up. Then, when people are diagnosed with endometriosis, people in their lives are in disbelief that the person with endo’s symptoms had been so severe.

The many examples I have cited from the data point to a pattern of performing wellness across the sample of people with endometriosis that I interviewed. The common thread of showing up, acting healthy, and performing wellness captures the internalized cultural expectations that people with endometriosis navigate. The pressure to be healthy leads to adverse effects for people with endometriosis, including feelings of isolation or confusion about how to engage their doctors in discussions about what they have been feeling. While the disease is so prevalent across people with internal reproductive anatomy, it remains taboo to express publicly the symptoms associated with endometriosis and menstruation, creating a tension between the person living with endometriosis and how they perform their reality.

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[145] Cook, *Stop Endometriosis and Pelvic Pain*, 13.

Reflections on Endometriosis Self-Help and Performing Wellness

A close critical appraisal of the endometriosis self-help genre paired with an analysis of interview data from conversations with people living with endometriosis provides a unique look at culturally produced expectations of people living with endometriosis and how people with endo enact those ideals through behavioral patterns. Cultural expectations that people with endometriosis are responsible for taking control of their health and should find ways to manage their disease on their own lead many people living with endometriosis to adopt performing wellness as a survival mechanism. People with endometriosis learn to mask their symptoms as a strategy to manage life with their chronic illness. Throughout this chapter, I have argued that the cultural ideologies reified through the rhetoric of endo self-help texts teach people that endometriosis is something to be managed individually. As a sociological issue, the medical institution needs to take seriously the impact of endometriosis, pivoting to a proactive approach to diagnosing and treating endometriosis, rather than a reactive response to patients who are rushed into emergency surgeries after years of living with symptoms related to the disease. Further, the internalized pressure to hide symptoms of endometriosis lead people living with the illness to perform wellness, which I suggest acts as a contributing factor in the delayed diagnosis of endo. Although it is not the fault of the person living with endometriosis, their learned approach to hide their symptoms and rely on self-help texts to manage their illness acts as a barrier to their successful treatment and recovery from endometriosis.

In this chapter, I have identified how endometriosis self-help texts often catch readers attention through promises of successful healing that one can achieve on their own by following the recommendations of the self-help text. Presenting a solution to “beat,” “outsmart,” or “heal” endometriosis to readers provides unrealistic assumptions about the control one has over their health outcomes related to endo. Although there are some useful approaches to support healthy living and improve overall health detailed within the mainstream endometriosis self-help texts, there remains a trend of omitting the importance of deep excision surgery as part of the treatment to remove the disease from the body, or at the least, this information is buried deep in the text. The result is cultural messaging that promotes the idea that healing is an individual endeavor that a patient must navigate themselves. People with endometriosis who educate themselves through endometriosis self-help texts might feel charged with taking responsibility for their illness and feel pressure to act well when they are struggling to manage their symptoms. Throughout my analysis, I have offered some suggestions for how a reader can carefully critique the self-help texts they engage, to avoid placing too much responsibility on themselves in their search for relief.

Aligned with the “pull yourself up by your bootstraps” rhetoric of self-help texts, many people living with endometriosis report a pressure to perform wellness, a term I define as the pressure to act as though one is in good health while they are suffering from invisible symptoms or experiencing pain and discomfort in the presence of others. The pressure to embody gender-conforming behavior presses people living with endometriosis to mask their symptoms. For example, rather than curling up in a ball or holding their abdomen, people with endometriosis stand up straight or continue engaging in regular conversation as though they are not dealing with distracting pain or symptoms. While people with endometriosis adopt performing wellness as a strategy to manage their daily obligations, the continual practice of hiding one’s symptoms might contribute, in part, to the delayed diagnosis of endometriosis.

I caution folks living with endometriosis against acting like their symptoms are not having a drastic impact on their daily lives, because performing wellness can pose a barrier to getting a proper diagnosis and subsequent treatment when hiding symptoms from doctors. Embedded in the practice of performing wellness is the cultural understanding that it is not considered appropriate to demonstrate signs of pain and suffering publicly, especially when it is related to menstruation. After mastering the art of hiding symptoms and downplaying their lived experience with endo, people with endometriosis might have difficulty sharing their experiences when talking to doctors. Perhaps people with endo get accustomed to the idea that what they are experiencing is manageable, so they do not convey their symptoms to their doctor in effective ways. For example, a doctor might ask if their symptoms get in the way of the patient's work. While a patient's symptoms are severe, due to the need to continue bringing home income, a person with endo pushes themselves to go to work, even if their symptoms are severe. Therefore, there can be mixed interpretations of how severe the symptoms are because on the surface it appears the patient is still able to continue their work, even if they return home to collapse and spend all their free time laid up in bed with a heating pad while taking pain medication. The cultural expectations lead to learned behavior patterns that obstruct diagnosis.

When someone rehearses behavior repeatedly, it becomes a habit, so for many with endometriosis, I expect that it took time for them to finally recognize and report their symptoms to enough doctors to get diagnosed. The pressure to avoid discussing menstrual-related issues limits the vocabulary and capacity to have these important conversations for those living with endometriosis, whether it is with their friends, family, or doctor. Additionally, the pressure to hide symptoms, specifically related to menstruation, reproduce patriarchal expectations that menstruation and women's pain should be hidden.

The many examples I have cited from the data point to a pattern of performing wellness across the sample of people with endometriosis that I interviewed. The common thread of showing up, acting healthy, and performing wellness exemplifies the internalized cultural expectations that people with endometriosis navigate. While the disease is so prevalent across people with internal reproductive anatomy, it remains taboo to express publicly the symptoms associated with menstruation, creating a tension between the person with endometriosis who performs wellness and their lived reality.

The rhetoric of wellness puts pressure on someone living with endometriosis not only to navigate it on their own, but to also hide their experience publicly because it is not considered an appropriate experience to share en masse. Rather, people living with endometriosis have been siloed and pressed to find a way, alone. A network of cultural forces and expectations leads many of the folks who do reach a diagnosis for their endometriosis to defy cultural and gendered expectations. Rather than succumbing to the patriarchal pressure to remain silent and uneducated about their reproductive health, people with endometriosis must speak openly about their symptoms and educate themselves through multiple approaches. Maya Dusenbery suggests in *Doing Harm*, "Advocates say individual patients can also create some bottom-up pressure for change by becoming informed themselves and bringing up the issues with their own doctors."[146] As I will discuss in the next chapter, throughout my interviews, I learned that folks who receive an endometriosis diagnosis often report the role of self-advocacy and self-education in their journey for answers.

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[146] Maya Dusenbery, *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*, (New York: Harper One, 2018), 58.

Chapter 3: Advocating for Self: Towards Endometriosis Diagnosis & Epistemic Justice

An Apology to Myself

I am sorry
I didn't believe
In my own pain
Until I gathered
The courage
To share my life
Out loud.[147]

I first heard the term endometriosis from a coworker at the diner where I served. After years of suffering from prolonged, heavy bleeding, my symptoms worsened. I started to experience painful cramps both during and leading up to my period. I was fatigued, nauseated, and struggled with throbbing and stabbing pain in my abdomen throughout the month. During one conversation about how I was struggling to manage work while feeling so terrible, my coworker looked at me and said, "Arline, I think you have endometriosis. That's what my daughter just had surgery for. It sounds like what you are describing." After years of telling doctors that something was wrong with my menstrual cycle and being prescribed birth control to "regulate it," my coworker finally gave me the key to unlocking my eventual relief from endo- a search term.

I started to look up endometriosis and was both excited and nervous that what I read felt so familiar. Once I had a name for what I was experiencing, I was equipped to bring that information to my primary care doctor. When I went to my doctor, I told them that I thought I had endometriosis, and to my surprise, at 23-years-old, my doctor finally took my symptoms seriously and said, "It sounds like you might have endometriosis." I was referred to a specialist

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[147] Maggie Bowyer, *When I Bleed: Poems about Endometriosis*, (Greensboro, North Carolina: Margaret Bowyer, 2021), 58.

and I had my first laparoscopic procedure a few months later. As I neared surgery, I trusted what the surgeon had to say, I felt I was in good hands and did not obsess over learning everything about endometriosis.

My recovery felt slow after surgery. As weeks turned to months, I started to wonder why I continued to struggle with the symptoms that led me to undergo surgery in the first place such as lower back pain, heavy flow, long periods, inconsistent cycles, and severe cramping throughout the month. I became passionate about understanding *why* I was still suffering, and I educated myself by reading books about endometriosis. I attended the free Endometriosis Foundation of America Patient Day Conference[148] and joined online endometriosis support groups. What I learned troubled me. I started to learn more about treatment options, I realized that although I trusted the first doctor who validated my condition and offered me treatment through surgical intervention, the operation that I had undergone was not the gold standard treatment for endometriosis. My first surgery never led to relief, although it did provide me with a diagnosis, or at least an educated guess.

Following my failed first surgery, through my self-education, I identified a specialist who would be able to help me recover and live symptom-free by completely removing the disease from my body using the best known methods for treating endometriosis: deep excision surgery. While meeting with the specialist and preparing for my second surgery, they requested pathology reports from the prior procedure to verify the presence of endo. When I called the first surgeon's office to obtain the records, they told me that no pathological reports were available because since the first surgeon had burned the tissue, there was no material to test. I had an observational diagnosis, not a medically confirmed one. Leading up to my second surgery, I was much more

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[148] To learn more information about the Endometriosis Foundation of America's Patient Day Conference, visit: https://www.endofound.org/patientday

prepared. I knew what questions to ask, I knew what the medical terminology meant when I spoke to the surgeon during the consult, and I knew that if I was going to get relief, I had to advocate for myself. In the appointments leading to my second surgery, I was clear about my expectations and asked the surgeons whether they felt they could meet them and how they would do so.

My second surgery led to a medically established diagnosis of endometriosis through the pathological confirmation of samples of excised abnormal tissue. Not only had the first surgeon failed to validate my diagnosis through pathological testing of tissue, but the methods used during the first surgery did not effectively remove all the endometrial tissue, leaving some behind to continue to grow. Unlike so many others living with endometriosis, it only took two surgeries for me to be diagnosed and treated. I felt relief that after the long journey, I finally knew that everything I experienced was real, had a clear cause. The endometriosis was removed from my body so I could begin the road to recovery and a mostly pain-free life.

Medical Experts and the Perpetuation of Epistemic Violence

Throughout my interviews, it became apparent that the research question driving my dissertation—why there remains a ten-year-delay to endometriosis diagnosis—was entangled with broader questions about how people living with endometriosis experience their life before and after diagnosis. For people living with undiagnosed endometriosis, of which most identify as women, the cultural challenge to demonstrate how much pain they are experiencing while not portraying themselves as overdramatic is a difficult line to straddle. As Maya Dusenbery says in *Doing Harm*:

> With no observable cause of the pain, the patient's expression of pain is the only evidence for it. But women's expressions of pain—whether through words, grimaces, or tears – are so often viewed as emotional that many women with chronic pain feel as though they need to be ultrastoic to be taken seriously.[149]

Dusenbery's claims align with the argument I made in the previous chapter, through which I explained that people living with endometriosis tend to perform wellness to avoid creating caricatures of themselves in relationship to their suffering. Although people with endo are facing debilitating symptoms, their illness remains invisible and navigating expressions of their illness remains entrenched in gendered expectations of womanhood. Throughout my conversations with people diagnosed with endometriosis, I started to learn more about how important the themes of self-education and self-advocacy were in the diagnosis process. Thus, in this chapter, I explore how self-education and self-advocacy serve in the process of endometriosis diagnosis, through interviews in which patients share that their self-education provided leverage towards reaching a diagnosis from their doctors. I also examine how endometriosis extends beyond the physical symptoms of the disease into the realm of mental health and how people with endometriosis described their experience once they were diagnosed. I argue that my project is a manifestation of epistemic justice because I have centered the firsthand accounts of those living with endometriosis as medical experts on their illness.

The themes of self-education, self-advocacy, the relationship between endometriosis and mental health, and diagnostic validation emerged from data collected through the one-hour Zoom interviews I conducted with eighteen people with endometriosis from the United States. Asking questions[150] related to participants' comfort with speaking about menstruation and misdiagnoses yielded discussions about how people became educated about endometriosis, specifically what

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[149] Maya Dusenbery, *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*, (New York: Harper One, 2018), 189.

[150] See Appendix B: Interview Questions for a complete list of interview questions.

role they had in learning about the disease. Participants from the sample shared that their research about their symptoms often led them to feel more empowered when approaching their medical appointments. Some participants learned about endometriosis and felt that they could then bring their knowledge to their doctors to request a diagnosis, demanding a laparoscopic procedure to finally investigate the underlying cause of their symptoms. With more knowledge of their symptoms and potential diagnosis, participants in my study share how self-education led to self-advocacy that often transitioned to a diagnosis. Once diagnosed, people living with endometriosis can better reflect on the emotional and mental toll that their illness has had on their experience. Learning that the years they spent suffering have a biological cause within their body led to deep feelings of validation that their symptoms were not all in their head.

The participants in my study, like other people living with endometriosis, faced an average of eleven- and one-half years living with symptoms without diagnosis, with some struggling for upwards of twenty-eight years. Although ten percent of people with internal reproductive anatomy live with endometriosis, and endo can be diagnosed through a commonly performed laparoscopic procedure, there remains a widespread trend of delayed diagnosis. In chapter one, I engaged with how the normalization of menstrual-related symptoms, coupled with the taboo associated with menstruation, begin to explain some of the cultural ideology that influences the delayed diagnosis of endo. Mirroring cultural myths of menstruation, sexist medical ideologies get reproduced in networks of power that construct women as unreliable informants, even when they are speaking about their firsthand experiences with symptoms. In chapter two, the themes of normalized conceptualizations of menstrual pain and the internalization of pressure to perform wellness begin to explain how cultural factors delay the diagnosis of endometriosis. However, there is more to the story. Those people with endometriosis who participated in interviews with me spoke often about how their doctors did not evaluate their reports of debilitating symptoms adequately. Thus, the interviews with people living with endometriosis highlight a site where medical knowledge is contested. The people with endometriosis I spoke with explained how they had to educate themselves because doctors did not place value on the patient's knowledge.

Due to knowledge asymmetries in medical contexts, epistemic norms dominate the knowledge considered credible, "…privileging the knowledge derived from medical training and theory, rather than that potentially rooted in patient experience, which effectively limits epistemic authority to healthcare practitioners."[151] This dichotomy represents potentially dangerous forms of epistemic injustice when it comes to patient-centered healthcare. Carel and Kidd suggest, "…asymmetries, dependencies, and power relations can increase the vulnerability of patients to epistemic injustice."[152] People fighting illness, like endometriosis, are already vulnerable to the repercussions of undiagnosed pain and mental health challenges incurred due to the process of seeking treatment for their undiagnosed illness. It is important for medical practitioners and educators to reconceptualize how medical knowledge is produced to ensure that the firsthand accounts from people suffering symptoms from endometriosis have a voice in shaping what we know about the illness. Ten years is a long time to live with unexplained pain, prolonged and heavy bleeding, bowel issues, leg pain, or fertility challenges. If the experiential knowledge from people living with endometriosis continues to be disregarded, then we continue to participate in creating the conditions of the delayed diagnosis of endometriosis.

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[151] Havi Carel and Ian James Kidd, "Epistemic Injustice in Medicine and Healthcare," In *The Routledge Handbook of Epistemic Injustice*. (New York: Routledge, 2017), 336.
[152] Carel and Kidd, "Epistemic Injustice in Medicine and Healthcare," 336.

Endometriosis literature has examined the trend of patients' distrust of or critique of the expertise of doctors.[153] Specifically, Whelan shares how people with endometriosis "challenge medical authority and develop patient-centered knowledge claims."[154] The ambiguity of endometriosis demonstrates a space of, "epistemic resistance," in which patients discredit their physicians as, "confused, ignorant non-experts."[155] Endometriosis is perplexing in nature due to inconsistent patient-symptom-profiles and the lacking correlation between symptomology and size or location of growths. Thus, endometriosis poses, "a particular source of physician-patient conflict," because the subjectiveness of pain severity and the invisibility of the disease results in tensions because "patient and physician accounts of endometriosis may directly contradict one another."[156] The contradictory accounts of endometriosis represent the tensions between physician knowledge as medical expert and patient knowledge as an individual who experiences the disease firsthand. Whelan argues that because of the challenges observing endometriosis and the common patterns of patients being dismissed, people with endometriosis form an "epistemological community" through which they share, "knowledge and a set of standards and practices for developing and devaluating knowledge."[157] My work extends Whelan's argument through collecting data representative of the endometriosis epistemological community to explore how the community acts as a result of their developed distrust for the medical establishment. Further, I situate the trends of self-education and self-advocacy in the context of

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[153] Emma Whelan, "'No one agrees except for those of us who have it': Endometriosis patients as an epistemological community," (*Sociology and Social Anthropology*, 2007), 959; Kate Young, Jane Fisher,& Maggie Kirkman, "Partners Instead of Patients: Women Negotiating Power and Knowledge within Medical Encounters for Endometriosis," (*Feminism and Psychology*, 2020), 28.

[154] Whelan, "'No one agrees except for those of us who have it,'" 959.

[155] Whelan, "'No one agrees except for those of us who have it,'" 958.

[156] Whelan, "'No one agrees except for those of us who have it,'" 957.

[157] Whelan, "'No one agrees except for those of us who have it,'" 958.

the patient-doctor relationship, arguing explicitly that the negation of patient knowledge as medically viable is an example of epistemic injustice.

Approaching the doctor's office as an arena of struggle, the power dynamics of doctor and patient living with undiagnosed endometriosis is a site of epistemic injustice, in which the patient's knowledge of their body is not valued like the medical knowledge the doctor has established through training. The theory of epistemic injustice framework provides a lens through which to critique how medical doctors are seen as the authorities on medical knowledge and their patients are not valued as knowledgeable informants. Epistemic oppression, understood as the, "… routine and harmful exclusions from some domain of knowledge production,"[158] provides a starting point for discussing the phenomenon of endometriosis delayed diagnosis as a result of patient-doctor dynamics. Doctors participate in epistemic violence through negating patient agency as producers of medical knowledge in general. Marginalized folks, in this case, people living with endometriosis, do not have access to the same epistemic tools as their doctors, who are in positions of power because of their situatedness within the larger context of society. The reliance on knowledge production by and for dominantly positioned social actors, such as doctors, limits the emergence of epistemic contributions by marginalized knowers, such as patients, resulting in the further marginalization of those folks. The dismissal of symptoms reported by people with endometriosis excludes patients' knowledge of their bodies as relevant in medical epistemology.

Endometriosis literature has focused on how people with endometriosis navigate education and power within their relationship to doctors in search of endometriosis diagnosis and care. Young et al. report in "Partners Instead of Patients," that "…patients' knowledge of their

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[158] Kristie Dotson, "A Cautionary Tale: On Limiting Epistemic Oppression," (*Frontiers* Volume 33, no.1, 2012), 36.

own bodies has historically not been valued in the medical encounter, being viewed as subjective and inferior."[159] Endometriosis research reports the delegitimization of endo patients' claims of symptoms. Facing doctors that do not value their reports of symptoms, people with endometriosis are not encouraged to share their embodied knowledge with their doctors. Young et al.'s findings suggest that, "medical education needs to equip doctors with the skills to acknowledge and incorporate women's knowledge of their bodies within the medical encounter, and to understand how their practice can foster (or impede) women's full social and economic participation."[160] Thus, this chapter extends into the realm of creating literature in support of an epistemic justice approach to endometriosis research, through which the people living with endometriosis are considered experts on their disease.

The long delay in diagnosis of endometriosis tends to represent a series of dismissals or misdiagnosis of endometriosis, regardless of a shared narrative by those afflicted with the disease. Importantly, although people with endometriosis report their symptoms, they are not often heard by their doctors. The people with endometriosis who participated in interviews were capable, as Carel and Kidd have theorized of ill persons, of explaining their experiences to a general audience.[161] However, the discussion of endometriosis is inherently inappropriate in the context of United States culture, which presumes that menstruation is taboo. The taboo associated with menstruation is an example of the refusal of doctors to integrate patient accounts as valid in the process of diagnosis, as well as useful in medical epistemology. Through participating in interviews and sharing their experiences, the people with endometriosis whose voices are highlighted in this chapter, and dissertation at large, have rejected culturally gendered

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[159] Young et al., "Partners Instead of Patients," 25.
[160] Young et al., "Partners Instead of Patients," 37.
[161] Carel and Kidd, "Epistemic Injustice in Medicine and Healthcare," 341.

expectations to remain silent. Instead, the act of speaking about their experience with symptoms and diagnosis of endometriosis serves as an example of epistemic justice. My project centers participant accounts by framing their stories as valid medical knowledge in the context of endometriosis research as an attempt to reconcile the epistemic oppression the endometriosis community has faced. Their expert awareness of endometriosis is a result of their lived experience managing the disease. Historically, medical research has not taken people's testimony seriously. The participants in this study reject the cultural silencing of their experiences to contribute to the medical knowledge we now have on endometriosis and the phenomenon of delayed diagnosis.

In this chapter, I reference the eighteen interview transcripts to show how people living with endometriosis often become fed up with their struggles to find a diagnosis for their illness and start to seek answers on their own. To do this, I analyze the relationship between common themes such as self-education, self-advocacy, mental health, and diagnostic validation. Straying from culturally taught expectations that menstruators should remain silent about their periods, I engage with the examples from interviews that emerged regarding the role of self-education and self-advocacy in the diagnosis of endometriosis. Once people with endometriosis learn more about their symptoms and disease, they can bring their knowledge to doctors and advocate for diagnosis and treatment. Later in the chapter, I emphasize what participants shared about the relationship between their chronic illness and mental health. Since people with endometriosis suffer for a disproportionately long time before getting diagnosed, there tend to be additional mental health symptoms, as reported by my participants. Finally, to conclude, I highlight comments that participants offered about the effect of receiving a diagnosis. Concluding the chapter, I move beyond the delayed diagnosis of endometriosis, to evaluate what it means for people who live in anguish for about a decade to finally learn that what they had been told was just a part of life was rooted in a diagnosable illness.

I argue that although it is useful to educate oneself and advocate for one's health within medical contexts, the emphasis that participants placed on the importance of self-education and self-advocacy further amplifies the cultural ideologies discussed in the previous chapter, in which the pressure to live healthy is constructed as an individual endeavor in United States contexts. Thus, while the stories that participants shared are empowering, I am careful to underscore the damaging cultural pressures at play that lead to this type of individualized role in health. The responsibility for those living with endo to self-educate and self-advocate to obtain a diagnosis reflects pitfalls of a sexist medical system that dismisses patients' complaints of menstrual-related symptoms. In the following sections, I critique how those in my sample who did receive an endometriosis diagnosis felt that they were charged with playing a pivotal role to achieve a diagnosis in the face of medical dismissal.

The Role of Patient Self-Education in Endometriosis Diagnosis

After years of being dismissed by doctors, friends, family, or colleagues, people with endometriosis might find themselves fed up and eager to get to the bottom of their symptoms on their own. As an unfortunate effect of a sexist medical system, the cultural ideologies related to menstruation and complaints of menstrual symptoms are met with dismissals by doctors that can cause long delays in the diagnosis of endo. In the interim, the growth of endometriosis below the surface gets worse and each passing year might lead to advanced stages of the disease.[162] Throughout the interviews I conducted, many participants emphasized the importance of self-

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[162] "Endometriosis Stages: Understanding the Different Stages of Endometriosis." Endometriosis: Causes - Symptoms - Diagnosis - and Treatment, March 18, 2021. https://www.endofound.org/stages-of-endometriosis.

education in their search for diagnosis. The role of self-education has been emphasized by many participants, and some explain that knowing about the disease and treatments is important to avoid accepting the first treatment one is offered. Raya, a 29-year-old from California says:

> It's annoying that we have to do our own research but like, to make sure that people are doing their own research and like, are finding specialists and aren't just letting the first person who says, 'You have endometriosis,' cut into your body just because you're finally like, relieved that someone believes you. Because you know, those unnecessary surgeries then lead to like, further complications down the line. Some people have more pain because of them.

Raya's comments highlight that for those who have been seeking external validation of their illness from doctors, it can be easy to trust the first person who suggests they have a treatment. However, patients must be careful to seek specialists who practice using the best available methods. The tendency of doctors to dismiss patients with endometriosis lead patients to accept help wherever they can get it.

Demonstrative of the dismissal of patient symptoms is a unique pattern of misdiagnosis amongst participants who identified as African American or multi-racial women of color. Across my interviews, women of color were disproportionately misdiagnosed with Pelvic Inflammatory Disease (PID) and sexually transmitted disease (STD), which can delay the diagnosis of endometriosis. PID is caused when sexually transmitted bacteria spreads from the vagina to the uterus, fallopian tubes, or ovaries.[163] Women of color participants were more likely to share that they were misdiagnosed with PID, that doctors questioned them about having STDs when seeking treatment for their endo symptoms, and that despite their understanding of the relationship between PID and STDs, the doctors were unyielding that this was their diagnosis.

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[163] "Pelvic Inflammatory Disease (PID)," (Mayo Clinic. Mayo Foundation for Medical Education and Research, April 30, 2022), https://www.mayoclinic.org/diseases-conditions/pelvic-inflammatory-disease/symptoms-causes/syc-20352594.

Since PID is often caused by STDs, doctors make assumptions about their patient's engagement in sexual activities if they do not inquire directly. Valerie, a 31-year-old woman who identifies as African American, Hispanic, and Native American shared that she went to the ER with pelvic pain that was so intense that she could not bend over to tie her shoes:

> They misdiagnosed me with Pelvic Inflammatory Disease. And they had a nurse practitioner look at me. And I was like, this doesn't make sense, like, I wasn't sexually active at that time. I was nineteen. I was still a virgin. So, I was like, doesn't pelvic inflammatory disease sometimes come from STDs? I kinda started reading and I was so confused.

Valerie explains the confusion and uncertainty she experienced when finding contradictions between her knowledge of PID and what the emergency room doctors were diagnosing her with. In disbelief, Valerie started to read more about the disease. Patients put faith in their doctors to assess the complete picture of their health and make recommendations accordingly. However, despite her status as sexually inactive, the doctors persisted that Valerie had PID, which might be influenced by medical biases about women of color's sexual practices. Additionally, Tanya, a 37-year-old woman who identifies as African American said:

> When I was making all of the ER visits, I actually was deferred to an OBGYN. So, I went to her with all of my symptoms and she said, well maybe you just have an untreated STD. Let's just give you some antibiotics and give you a new type of birth control. Just try that and come back in a year. And I'm like first of all, I don't have an STD. Everything was negative. I haven't had sex in a year because I've been in so much pain. Something is wrong.

Here, the doctor presumed that Tanya was sexually active and might be living with an untreated STD. The doctor did not ask Tanya about her recent sexual activity or discuss the possibility with Tanya, but applied their stereotypes to Tanya instead. This left Tanya frustrated and dismissed for her symptoms.

After going through surgery because of an ectopic pregnancy, Grace, a biracial 30-year-old woman who identifies as African American and White shared that she was victim to doctors prejudiced assumptions about her sexual history as well. She says, “When I was in the hospital after the surgery when the doctor came to remove the bandages she said, ‘So have you experienced a lot of STDs?’” Grace told the doctor she had not, and the doctor continued, “That’s what we normally see in patients with ectopics.” Grace was frustrated that the doctor put the blame on her for having an ectopic pregnancy. It is common for people with endometriosis to have an ectopic pregnancy, which can be excruciatingly painful. There is additional emotional pain from losing a baby due to the implantation in the fallopian tube rather than uterus. The insensitivity of doctors towards Grace’s sexual history and current condition demonstrates a disregard for the patient that is dehumanizing and could lead to medical trauma. Such trauma could leave endometriosis patients disinterested in seeking treatment and could result in a further delay to diagnosis of the underlying disease. However, across my sample, reports of racist misdiagnoses led many participants to self-educate.

The patterns reported by women of color participants were consistent with findings from other research, such as that of Dorothy Roberts. Paired with the ongoing assumptions that Black women are less likely to have endometriosis, there are beliefs that they are more likely to live with PID. Such assumptions are indicative of the bias in medicine that would presume that Black women are more likely subject to complications resulting from STIs. Pelvic Inflammatory Disease is often treated with sterilization, thus the correlation between endometriosis misdiagnosis in Black women leads to more sterilization efforts.[164] The disproportionate misdiagnosis of women of color with PID is indicative of racist assumptions that African American’s and women of color are more likely to engage in unprotected sex. Thus, women of color are victims of medical racism when seeking medical help for pelvic pain. Due to the long-

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[164] Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty*, (New York: Vintage Books, [1997] 2017), 255.

lasting misconceptions about who is likely to be diagnosed with endometriosis derived from the misnomer “career woman’s disease,” it has been found that “African American women were frequently misdiagnosed with pelvic inflammatory disease caused by untreated sexually transmitted diseases. This buys into the false assumption that African American women are sexually promiscuous and unclean.”[165] Therefore, for some participants in my sample, their racial identity seemingly factored into the types of misdiagnoses they received when seeking treatment for pelvic pain or ectopic pregnancies, which represents additional barriers for these women’s access to timely diagnosis.

Although participants shared their encounters with misdiagnosis of PID and STIs, in each case, the participant was educated enough about sexual wellness to understand that the diagnosis was a misperception. Although doctors continued to dismiss their symptoms as unremarkable, Valerie, Tanya, and Grace each shared that they knew something was wrong and turned to other resources to learn about the underlying cause of their symptoms. The patterns of self-education were consistent across the broader sample.

Many participants from the sample discussed the lack of menstrual health education presented to young menstruators. Today, the internet facilitates opportunities for people to gather information and research about their difficult to explain illnesses. Participants told me that they learned a lot of useful information about endometriosis through watching YouTube videos, joining Nancy’s Nook on Facebook, engaging the chronic illness Instagram community, or Googling extensively. Technology provides folks with undiagnosed endometriosis a tool to learn more about their symptoms through keyword searches. Relatedly, I emphasize examples from

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[165] Nancy Arden McHugh, *The Limits of Knowledge: Generating Pragmatist Feminist Cases for Situated Knowing*, (Albany: State University of New York Press, 2015), 28.

the interviews that demonstrate how participants discussed the role of self-education in their journey to diagnosis.

The data from the interviews I conducted support findings in Whelan's 2007 article, which emphasizes how people with endometriosis tend to self-educate in response to their poor experiences with doctors. Whelan claims that because physicians did not take endometriosis seriously, their patients would themselves "become experts."[166] However, I extend this argument over a decade later to engage with the continued lack of epistemological credibility that people with endometriosis receive. For audiences such as medical experts, employers, and insurance agencies, the experiential accounts from people with endo do not carry "epistemological weight."[167] Thus, while people with endo might construct an epistemological community, the community is still confronting epistemic injustice because their knowledge and accounts have not been validated as medically significant.

The lack of awareness of menstrual-related disease is represented in patient comments about menstrual education. In our conversation, Peyton, a 23-year-old from Washington brought up how young people are taught about menstruation. Peyton said:

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[166] Whelan, "'No one agrees except for those of us who have it,'" 964.
[167] Whelan, "'No one agrees except for those of us who have it,'" 967.

> Our understanding of periods and how we educate young women impacts the way that they approach their illness. I think if I had had more compassion, and a more thorough education of what periods are supposed to be, and then what endometriosis is, I think there would have been a lot less self-flagellation, a lot less self-deprecation. I've lost a lot of my worth from having this illness because of the way that it was marketed to me. And I think that that's something that we definitely need to change. And that needs to be implemented into education in the future, because it's as common as diabetes, one in ten people with uteruses have endometriosis. There needs to be wider access to this information, and it needs to not be, 'Oh, well, the cells in your uterus go outside.' Like, that's not what it is. And that's a horrible explanation of it. And I think that's something to know is that the familial aspect is major and the way that we are educating young people with uteruses. And then also how it impacts people in the workplace, and how lasting the way that we talk to our workers impacts them. To this day, I cannot stand hearing the words 'power through' because I would have managers where I would literally be on the floor, and they would tell me to 'power through.' I think overall, there just needs to be more compassion for women in general, but then also when it comes to period pain, and then also those with endometriosis. It is not easy to fucking live with.

Peyton's reflections highlight how the lack of information about endometriosis included in menstrual education led her to have low self-esteem because of her illness. Peyton's inability to understand why it was that she was suffering caused frustration. Further, Peyton critiqued widespread explanations of endometriosis for being too limited. Although endometriosis physiologically refers to the growth of endometrial-like tissue outside of the uterus, Peyton emphasizes the limitations of only defining endometriosis as such. Rather, a thorough account of the disease would highlight the familial aspect, which is that you are more likely to have endometriosis if you have a mother or sister with the disease.[168] Additionally, Peyton connects the lack of endometriosis education to the workplace, highlighting the damages incurred by folks living with endometriosis in work contexts that cannot understand their disease. The example from my conversation with Peyton underscores a general awareness by those living with endometriosis that public menstrual education is lacking in-depth explanations about what to

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[168] "Endometriosis." Yale Medicine. Yale Medicine, August 11, 2022. https://www.yalemedicine.org/conditions/endometriosis.

expect. Menstrual health should include what signs menstruators can look out for regarding endometriosis such as experiencing longer, heavier bleeding, or cramps between periods. Peyton emphasizes the pitfall of limited menstrual education and then connects it to real-world challenges such as going to work in an environment where the supervisors do not understand endometriosis either. For Peyton, improved education about endometriosis is an important factor that could help people living with the disease to identify it sooner.

Similarly, other participants emphasized how the lack of education about endometriosis extends into medical contexts as well. Grace, a 30-year-old woman who lives in Illinois commented on how people with endometriosis have to become self-educated and then are left to educate others. In our conversation, Grace shared that she likes to read medical journals to learn more. She says, “I may not have as much knowledge as you [doctors] because I did not go to actual school. But I self-educate, which is also important.” Grace’s commentary alludes to how people interpret her education as less valid in comparison to medically trained doctors. Contrarily, Grace’s firsthand experiences with endometriosis led her to learn more about the disease so that she now has a deep understanding of endo. Grace feels an obligation to share the knowledge she has gained about endometriosis:

> I feel like us as endo warriors have to be advocates but also have to educate, right? I have to educate you on my disease, I have to educate you as a doctor who went to school to learn about these things. Because you have not been educated. However, one in ten women have this disease. And there's all this misinformation flying around. So, for me having to educate doctors, it's exhausting. And it's upsetting. But what I realized is those of us in the endo community have literally come together to figure out our healing on our own.

Grace’s critique of doctors’ lack of education situates how many people with endometriosis feel in the context of their disease. Since many medical doctors do not jump to endometriosis as the cause of menstrual-related symptoms, people with endo suffer for years. In the meantime, many people with endo feel like they must take matters into their own hands and start to educate themselves about diseases related to their symptoms so that they can get to the bottom of their suffering. Thus, the eventual diagnosis of people with endometriosis can often be attributed to their role in learning about the disease and then bringing it to their doctor. The preparedness that Grace demonstrated through her experience aligns with how Whelan presented the role of self-education:

> A chronically ill person who understands her disease from a medical as well as an embodied perspective may be better able to evaluate her doctors' claims, to contest them if necessary, and to have those evaluations and contestations validated, because she can present herself as a knowledgeable agent, rather than a hysterical hypochondriac.[169]

For folks struggling with endometriosis, knowledge does translate to power. In some cases, the diagnosis of endometriosis is not a prolific moment that represents the end of their search for answers, but it is just the beginning. Sophia, a 37-year-old from California, shared that to her surprise and disappointment, after months of meeting with a doctor about her symptoms, the doctor casually mentioned at the end of one appointment that perhaps, it was in fact endometriosis that was causing Sophia's suffering. The series of events led Sophia to seek information for herself:

> And then at the end of one appointment, I was like, doctor, like, what is the hurt about? Like, why am I bleeding? So, like, what? And he actually said right before he left the office, like our eight-minute appointment, you know, 'I'm sorry, I think you might have endometriosis.' And then he walks out. And I'm like crying in the room by myself… So, I just leave his office in complete shock. And then I start the process of self-education. And then I realized what he had done. I was like, I can't go back to him anymore. And then I found Nancy's Nook through support endometriosis. Okay, so the first thing I did was sign up for a support group, because I was like, I can't go through this alone. If he's not going to help me, I have to help myself. So, I realized I needed to seek care on my own. And then I got recommended to see Nancy's Nook… So it was kind of like this thing where I didn't know for thirty-seven years. And then all of a sudden, like the blessing happened when I needed it. So, I only knew because my doctor accidentally slipped up and he said the word.

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[169] Whelan, "'No one agrees except for those of us who have it,'" 977.

Once Sophia's doctor mentioned the term 'endometriosis,' everything shifted. She felt like he was withholding information for the year she spent visiting him in follow-up appointments and then she describes it as a "slip up" when he finally said endometriosis in their appointment, which was a turning point in her journey to diagnosis. The contextualization of her doctor naming endometriosis as a mistake indicates the distrust that patients have towards their doctors after years of visits that do not lead to a diagnosis.

Following the interaction with her doctor, Sophia turned to the internet to educate herself about endometriosis. Sophia's story highlights the way that participating in online communities can help endometriosis warriors to connect with each other and share useful information that the doctors are not offering. In the process of developing knowledge in an epistemological community, folks living with endo "are simultaneously made vulnerable and empowered to challenge medical authority by the enigmatic nature of their disease."[170] Such as in cases like Sophia's, the mere knowledge of the search term 'endometriosis' opens opportunities to seek additional information about the disease and become part of a community to learn how to navigate the illness.

Sophia also describes the unique ways that the internet provides those suffering with endo an opportunity to identify with the illness through YouTube. She says:

> I've been watching a lot more YouTube videos which have been extremely educational and hearing the women talk about, 'Oh, I have endometriosis'… and I'm like, 'That sounds like me' and actually, not having a human, more… I think they call them parasocial relationships, but seeing those conversations, that's the social interaction that's allowed me to reflect on my own experience… I think there's a new emerging type of social relationship where somebody is kind of extremely forthcoming with themselves and puts themselves on a platform where other people can engage at their own comfort level so that definitely did give me a safe space to see a reflection of who I was rather than project who I was onto somebody else.

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[170] Whelan, "'No one agrees except for those of us who have it,'" 958.

Sophia shares how it was through the online exploration of endometriosis and listening to firsthand accounts through prerecorded videos that allowed her to start to recognize herself as someone with endo. Although in the past Sophia had thought of endometriosis as so severe that she could not claim the experience to be her own, the engagement through viewing YouTube videos deescalated the pressure to engage directly with someone else, and instead allowed Sophia to reflect. The process led her to recognize that the experiences that the YouTuber shared were similar to her own and she started to identify herself as someone living with endometriosis. The theme of self-education evidenced in interviews, such as with Sophia, corroborate Whalen's work, which suggests that people with endometriosis question their physician's claims and turn to alternative educational resources such as books, internet sources, or support groups to learn about the disease.[171] People with endometriosis, like Sophia, seek ways to learn about their disease using what little information they have received from their doctors as a launchpad.

Finally, participants like Tanya made note of how important self-education was in their process to diagnosis. Tanya, a 37-year-old from Mississippi said:

> I think self-education is the most important part of the journey. Because had I not learned on my own, I would still be so lost, probably still doing surgeries that are not effective, on birth control that was not effective. You know? There's so much that I would still be doing wrong had I not educated myself. So, I think it's very important for any situation that you're going through to educate yourself. For one, everything makes a lot more sense to you. And that way you can advocate for yourself, you know, you know, Lupron for example, you know, educate yourself on it, and you can say, 'Okay, well, I read this, this, this on this, and I'd rather not take it,' and speak up for yourself. So, I mean, it's very important, because if you don't know, then you're just going with the flow.

Tanya's explanation of self-education highlights the risks of relying too heavily on doctors to guide patients in the right direction. Learning about the treatment options and how to apply that knowledge in determining treatments was important for Tanya to disrupt the cycle of ineffective

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[171] Whelan, "'No one agrees except for those of us who have it,'" 966.

surgeries and medications that were not supporting her healing. Tanya's comments also highlight a critical theme that surfaced throughout my interviews, which is the emphasis on the relationship between self-education and self-advocacy.

While self-education can be a form of empowerment, it can often lead patients to engage in self-advocacy by taking the newfound knowledge and putting it into practice. While speaking to people with endometriosis, one of the most common pieces of advice offered regarding seeking treatment and diagnosis was to engage in self-advocacy and persist even when doctors do not seem to listen. The process of self-education shifts the patient's relationship to their illness because, "…it engenders a sense of empowerment and control over endometriosis itself."[172] Endometriosis warriors are often left to advocate for their health in the face of doctors who suggest that there is nothing wrong. This is not always an easy road when one is suffering debilitating symptoms that leave them weak and exhausted. However, in the following, I share examples from the interviews that show how self-advocacy serves a pivotal role in endo warriors' quest for comfort.

Self-Advocacy as Disruption of Gender Norms: The Right to Menstrual Health

As discussed in chapter one, the cultural messaging surrounding menstruation in the United States positions it as taboo, creating pressure for people with endometriosis to avoid discussing their symptoms publicly. The act of advocating for oneself in the context of getting diagnosed with endometriosis is a departure from learned gendered behaviors of keeping quiet about their menstrual symptoms and rejection of the learned practice to mask symptoms through performing wellness, as discussed in chapter two. Instead, self-advocacy is a repudiation of gendered expectations. The following examples of self-advocacy contradict the former examples

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[172] Whelan, "'No one agrees except for those of us who have it,'" 965.

of internalizing pain as normal and performing wellness discussed earlier. In the interviews, participants expressed how patient-doctor relationships often rely on the beliefs that the patient and doctor have come to perform, such that the doctor is the authority and patient is their subject to treat. However, once the person with endo shifts towards self-advocacy through speaking up for themselves, they tend to get more responses from their doctors. As a departure from gendered roles of submissiveness or silent suffering, self-advocating people with endo directly disrupt the gendered role ascribed to women, in which women are expected to offer comfort to others. People with endo who advocate for themselves reinscribe their gender in ways that develop what it means to live with menstrual related pain. Judith Butler says:

> Significantly, if gender is instituted through acts which are internally discontinuous, then the appearance of substance is precisely that, a constructed identity, a performative accomplishment which the mundane social audience, including the actors themselves, come to believe and to perform in the mode of belief.[173]

Although the cultural mode of belief in the United States has ascribed menstrual pain as a condition of womanhood, those with endometriosis who self-advocate for their health are actively constructing their identity in contradiction to hegemonic expectations. The act of seeking medical intervention for menstrual-related symptoms directs attention at what has been historically silenced, disrupting gendered expectations of women's menstruation. When women participate in the taboo of discussing their periods, they reject the roles ascribed to them and demand attention to that which is culturally constructed as unspeakable. People with endo who self-advocate construct identity as disjointed from their biological capacity, veering from the roles that society expects them to perform.

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[173] Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity*, (New York: Routledge Classics, 2007 [1990]), 192.

Throughout the interviews, there was a common theme of self-advocacy and participants emphasizing the role of advocating for themselves to reach a diagnosis. All the participants from my sample did receive a diagnosis for their endo and many participants specifically highlight the role of self-advocacy in the process through which they learned to speak directly and explicitly about their symptoms and the research they gathered about their illness. It is not uncommon among those diagnosed with endometriosis to report a sense that they had to force doctors to listen to them and force doctors to refer them to the gynecologist of their own choice.[174] Participating in self-advocacy is an example of epistemic justice because the participants knew that something was wrong with them and persisted in bringing their knowledge of their body and experience to the forefront of discussions with doctors to push for a diagnosis until doctors took them seriously. Voicing their experiences and articulating their struggles with endometriosis symptoms is a break from the gendered expectations of womanhood, and through advocating for themselves and asserting their knowledge, many folks from my sample did get diagnosed. The following examples from the interviews highlight the role of self-advocacy and what self-advocating for health means in the context of endometriosis diagnosis.

Once educated and equipped with information about their disease, people with endo share how they feel a sense of empowerment and confidence to advocate for their health. Charlie, a 28-year-old from Vermont, explained the connections between self-education and self-advocacy. Charlie shared the following comments regarding the role of self-education:

> I think it [self-education] is more important than anything. Because if I hadn't done that, again, I wouldn't have felt this fire to learn more. Like, something wasn't right. That's when I got to the Orlissa piece, that was the piece where it was like something, something isn't right here. And there has to be a better way. So, that's when I started Googling, endo everything. Right. And also trying to trying to utilize like, my nursing resources to try to find out more and reading all those books and stuff.

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[174] Helen Cox, et al., "Focus Group Study of Endometriosis: Struggle, Loss and the Medical Merry-Go Round," (*International Journal of Nursing Practice*, vol. 9, no. 1, 2003), 2–9.

Charlie, who works as a nurse, emphasizes how when her doctors prescribed her Orlissa, she started to feel passionate about learning more. The side effects of Orlissa were immediately noticeable to Charlie, and she realized that she was missing information about the big picture. Turning to the internet, Charlie began to learn as much as she could about endometriosis treatments. Although there is no quick fix or clear route from symptomology to treatment, self-education and self-advocacy can empower patients to work with their doctors to reach the best outcomes. Charlie said:

> I'm a lot more educated in the last two years, like I've done so much self-advocating, and like networking, and that kind of stuff that I've really found, like my voice in that. And I've connected with, like a team of doctors for the first time that knows how to help me. So, I feel a little more empowered, and educated.

Charlie struggled with visiting many doctors over the seventeen years it took for her to be diagnosed with endometriosis. However, once she started to self-educate and become more informed about the disease, she started to feel prepared to advocate for her health.

Communicating with a variety of doctors trained in different disciplines was a careful decision that Charlie was primed to initiate through her research about the complexity of endometriosis. Once she did start to speak up and take an active role in coordinating her care, she felt better educated and empowered to advocate for her health. While it is great that Charlie was able to learn about the disease and act upon that knowledge, I am cautious of reifying messaging that this is the way forward. Requiring patients' education and advocacy places unnecessary pressures on those struggling with endometriosis to then be responsible for learning about the disease and taking an agentive role in their diagnosis and treatment. The example of endometriosis delayed diagnosis and the role of self-advocacy emphasizes pitfalls in the current medical model, through which many people are left suffering for years with unexplained symptoms and must become educated to reach a diagnosis. Charlie explains how educating herself through reading about endometriosis empowered her to self-advocate:

> I mean, just asking questions— standing up and saying no— or 'tell me more about that.' Because for so long, for ten plus years, I just said yes to whatever my doctor offered and I didn't realize that it was happening over and over and over again until a couple years ago. I felt in my gut- they were trying to push Orlissa on me. And I was like, this doesn't sound right to me. As a nurse I was just saying like… this is a brand-new drug, they don't really know anything about it, they're trying to push it on me because they said a rep was just there. Like, nothing felt right. So, I just was like, hold up. I don't know. So, I took a trial packet of it home. Then, eventually my pain was so bad at times I did start it. But I only took it for two weeks and I still had that feeling of like, this isn't right. So that's when I started reading different books. That's when I found an endometriosis group on Facebook. That's when I started doing all of these things that helped get me to learn so that I could figure out for myself what was going on and I could find out what I needed because I knew that the doctors weren't going to give me the resources that I needed… or the current doctor…I finally found a doctor that I was really happy with here in Vermont but she recommended my excision surgeon. And she was the first person to basically be like, 'I want to be an expert at this, but I'm not quite there yet. Here's who is. I'd be happy to do your surgery, I'd be happy to do X, Y, and Z for you, but I also know that you've had two surgeries before and I'd like you to have this treatment.' She kinda like opened that door for me. Like, okay, I'm in control here and I can kind of figure out what's going to work.

Charlie's reflections on how she became aware that something was off about how she was being directed in her doctor's visits and then started to self-educate, which led to self-advocacy, is helpful in understanding the cultural dynamics of medical spaces that further entrench people with endo in the pattern of delayed diagnosis. Unfortunately, for many people with endo, a lack of medical awareness, unlike Charlie who is trained as a nurse, might lead them to assume that doctors always know best. Many people place so much trust in doctors that they are easily convinced that trying medications prescribed by doctors is the next step, but Charlie knew that when a drug representative comes to an office, there is a pressure for doctors to get patients to try the medicine. Charlie felt that things were not right and turned to research to make informed healthcare decisions. Thus, the education of both doctors and their patients should be closely considered so that, "…the interests of both women and clinicians are served by a medical encounter in which each party's knowledge (and power) is acknowledged and incorporated."[175] The collaboration between patients and their doctors can ensure that medical decisions are made with awareness and consent of both parties.

Like Charlie, Kylie, a 41-year-old from North Carolina describes the shift in her experience once she took charge by educating herself and advocating for her health needs. Kylie's diagnosis took twenty-four years to reach from the onset of symptoms. For decades, Kylie struggled from symptoms that she could not understand or attribute to a medical diagnosis. Over time, she became more involved with educating herself in an effort to get a diagnosis. Kylie said:

> When I was twenty, I was like, I didn't know what was going on. Like, I would go to the doctor and they would just try to write me a prescription for birth control and I was like 'No,' or I just wouldn't get it filled after…But I couldn't advocate for myself so much. Now I feel much more empowered to advocate for myself and take charge of it. I almost wish I had a daughter, I love my son, but I almost wish I had another young teenage girl to be like, 'This should not debilitate you every month for at least a week.' I wish someone had done that for me.

Since Kylie struggled for so long with endometriosis symptoms and dismissive doctors, she spent years dodging treatments that she did not see as necessary or helpful. In our interview, Kylie shared that as a lesbian, she had no interest in taking birth control pills because she did not prefer the disruption to her natural hormones. In her twenties, she was passive and simply would not get the prescription filled. Then, when she got older and had access to the internet, she started to learn more about her body. Once Kylie had an opportunity to explore options through internet research, she said she provided her iron studies to her gynecologist and demanded, "I want an ablation!" Kylie told the doctor, "I am tired of being tired. I'm tired of this…I tried the whole food plant-based—and I love it actually—but I'm tired of being tired. I had to be firm, and she

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[175] Young et al. "Partners Instead of Patients," 36.

was like, 'Yeah in 2020 no one should have to suffer from their periods.'" Even though Kylie had reported her symptoms for years to many doctors, it was not until she approached her doctor, records in hand, and expressed, "I want this," that she was taken seriously. Then, as Kylie explains, through advocating for herself, she felt more empowered. Kylie said that "As I get older, I feel so much more empowered now to demand things and advocate for myself." When she was younger, gendered expectations may have dissuaded her from approaching her concerns. Then, the transformation towards self-education and subsequent empowerment signifies the break from traditional gendered expectations that allowed Kylie to address her health concerns. Although Kylie's pursuit of self-education followed with self-advocacy helped to eventually reach an endometriosis diagnosis, the bigger picture is that the United States medical system allowed her to suffer for twenty-four years before being met with a doctor willing to investigate her symptoms.

While medical doctors are often looked to as the experts and given the authority as having the ability to help patients understand their bodies better, uniquely, some participants emphasized how in many cases, medical professionals complicated or confused patients about what they were experiencing. Lilly, a 33-year-old woman from Texas trained in public health shared that she is, "…more equipped than lay people" to understand what doctors are discussing. She said:

> I can like advocate for myself. And like, I understand things that are being said to me more than other people. And I understand when like jargon is purposely being used to confuse. Which is part of the reason why I do the work that I do, because like, you know, trying to be healthy and take care of yourself should not be rocket science. Like, this is my body, like, my body doesn't need to survive entry into our atmosphere. Like I need to know the basic things and what I need to do to keep myself healthy.

Lilly places emphasis on how at times, it seems that doctors are purposefully using exclusionary language with their patients. Using specialized jargon can keep patients out of the loop about what the doctor is really seeing or thinking. Uniquely, another participant, Sophia, had commented, “Doctors aren’t mind readers and they aren’t magicians. They can only go off the information that you give them.” However, Lilly’s point is that sometimes, doctors share information with patients in inaccessible ways to confuse them or perhaps, to overcomplicate the doctor’s explanations of what they can see. Many of the participants in my sample shared enough explicit details with their doctors to indicate that they might be living with endometriosis, and still struggled for an average of eleven- and one-half years to be diagnosed. It is not always a matter of patients withholding information, but sometimes doctors simply do not recognize endo in their patients. The lack of diagnosis leaves some patients hopeless, but for others, it is motivating to figure out their suffering on their own.

The current United States medical model leads many people living with endo without answers for years. In the meantime, they struggle to manage symptoms that seemingly have no cause. It is understandable that many people with endometriosis become charged up to take an active role in getting to the bottom of things because symptoms can be debilitating. Self-advocating is not easy in the context of a disease that has been culturally shaped as unspeakable. Brooke, a 27-year-old from Massachusetts shared with me that:

> I really do think I'm very in tune with my body. And if something doesn't feel right, I, I try to speak up and advocate for myself. But it's hard when you have all these expectations from you know, outside sources, you really want to be the best that you can be. But having endo it just really, it can drag you down.

Although Brooke shared a sense of self-awareness and claims that she is responsive to changes in her body, she noted that endo remains challenging because of the external pressures involved. Brooke said that she advocates for herself, specifically through speaking up about symptoms or things that do not feel right. However, the complex external forces, such as cultural messaging that menstrual pain is normal, can make it difficult for people with endometriosis to notice when something is wrong. To surpass the obstacle of medical misdiagnosis or dismissal, patients must overcome the cultural expectations and gendered norms that pressure them to remain silent about their menstrual health, and step into a leadership role in their health journey.

One participant was very detailed in her elaboration of what it means to self-advocate. Jade, a 42-year-old from California shared that self-advocacy is a skill she has developed because of her experience with endometriosis. Jade said:

> In advocating for myself, I am not afraid to tell people, 'No.' I've fired doctors. I have told people flat out I, I went in, met with a new general practitioner within the last year, and told her this has been my experience. These are things that I will not stand for anymore. And I'm sorry if I come off very brusque and very abrupt. But this is what is very important to me. And having just been through an experience where I had to fire a doctor, for questioning my mental health, I was not going to put myself in a position where I felt like I was essentially allowing someone to abuse me, because I was afraid to put a stop to it. I'm too old for that. And that's, I guess, that's what I mean, when I say advocating for myself or when I tell my patients to advocate for themselves. They have to be willing to tell people, 'Look, I think you're wrong. I'd like a second opinion. I'm sorry, I don't like what you're having to say. I'm gonna go see, someone else.' You know? Fighting for treatments is something that this is, this is what actually caused me to fire my doctor. I was asking, I was diagnosed recently this last year as being severely anemic. I've always been kind of up front with that, with endo it's very common. And when the doctor diagnosed me with anemia, I said, 'Well, you know, I have endometriosis.' And that's correct. And he went, 'I can't imagine that that's what's causing this situation.' And so, he and I went back and forth. He automatically wanted to put me on birth control, which messes with your hormones. And I was, I told him, I was not going to do that. We are trying to conceive if anyone's putting me on any kind of hormone, it's going to be my reproductive endocrinologist.

Jade's explanation illustrates some of the real-life interactions and challenges that people with endometriosis face, which amplify the importance of people with endometriosis learning to advocate for themselves. Jade is clear that she is not afraid to fire a doctor, which repositions the power dynamics of patient-doctor relationship from the doctor as authority to the doctor in service to the patient. Jade's quote captures many threads from the sample that I have discussed throughout this dissertation, emphasizing the damage she felt when a former doctor would dismiss her illness as mental, and highlighting how she felt pressure to educate her doctor. What stories like Jade's demonstrate about endometriosis delayed diagnosis is that even when a patient is well-educated, whether it is because of their background in medicine or their research about endometriosis, it is common that doctors have a different perception of the patients' situation. Unfortunately, what Jade's reflections show is that there remains tension between doctors and patients who bring knowledge to their appointments, and that sometimes patients need to cycle through multiple doctors before finding someone who listens. The challenges of self-educating, self-advocating, and then being heard puts pressure on the patient that can exacerbate the challenges they face as someone living with endometriosis. People with endometriosis should not spend a decade searching for answers, yet stories from patients such as Jade, whose diagnosis took twenty-eight years, highlight the shortcomings of a medical establishment that pushes patients to address their health concerns individually because their needs are unmet in medical contexts.

For many participants in my sample, self-advocating both offers them a sense of empowerment and points to the difficulty of being perceived as knowledgeable experts about their condition. However, I argue that people with endometriosis know their bodies well and are aware of their illness, often before they have a medical diagnosis. Some participants articulated that the role of self-advocacy is important because of the medical tendencies of dismissal. Tanya, the 37-year-old woman from Mississippi shared how important self-advocacy is while seeking endometriosis diagnosis and care. Tanya said:

> The first thing I will say is always be your own biggest advocate. Listen to your body. Because people will tell you things just to kind of brush you off. And sometimes it's simply because they don't know the answer. You know, some people are not comfortable with saying, I don't know. So, I think you need to be your own best advocate and continue to push through regardless of what answer you're given because you know your body better than anyone. And if you don't feel that something is right, and I will tell anybody go to as many doctors as you have to, to get the answer that you need. I mean, I've lost count of the number of doctors I've seen on this journey. But I wasn't going to give up because I knew something was not right.

Tanya’s advice is well-put, because she highlights that sometimes when doctors dismiss patients it is because they do not have an answer. Unfortunately, rather than saying that they are not sure, doctors often misinform patients by stating that they cannot see that anything is wrong with them or provide the misdiagnosis that what the patient is experiencing is “in their head.” Tanya encourages people to remember that they know their body best, and that if one doctor dismisses you to seek another. While this advice is clearly well-intentioned and is important, because if something is wrong with your health you should continue to seek answers, it also underscores deeper systemic issues of healthcare access. For many, visiting the doctor for multiple appointments, or going to see different doctors, is a costly and time-consuming endeavor that is not realistic amidst their other obligations.

Importantly, not every participant shared that they felt empowered to self-advocate. In some cases, interactions with their doctors led folks to feel defeated and retreat. For Peyton, the 23-year-old from Washington mentioned earlier, although she felt something was wrong with her, doctors’ tendency to prescribe birth control created a barrier to understanding what was going on beneath the surface. Peyton explains how her experience of treatment in Texas was different than when she moved to Washington, but that the experiences she had in Texas have shaped her outlook on medical professionals. Peyton shared:

> So, it was around seventeen. But I was like I think I have something wrong with me. I need to talk to a doctor about this. She just put me on birth control. I came back every year for my yearly until I was twenty... And she's like, '…but you don't want kids, or you're not interested in having kids, we don't know if you'll even have kids. So, like, let's just not worry about it, do yoga instead.' So, I kind of just stopped advocating for myself because I knew that it wasn't, that I wasn't going to be believed. So over time, I've really come to distrust medical professionals because they don't listen to my pain, they don't care about my pain, they're just going to prescribe me something and then send me on my way. But up here in Washington, it is very different, like, I still got the brush off, but then, um, they were having difficulties putting in my IUD. And so, they did an ultrasound, a pelvic ultrasound, and that's where we found it. Which was a twelve-centimeter black cyst that that had encapsulated both of my ovaries. And I got told if I hadn't come to Washington and hadn't advocated for myself, and that would have burst I probably either would have died, lost my ovaries, or had major damage done to my organs. It was bad. It was really, really bad. And so, do I trust them? No, I don't. Do I trust them more now being up here in Washington, little bit. But I just, I, I'm gonna be weary for the rest of my life, honestly.

Peyton's reflections on the experience of being medicated with birth control as a response to her symptoms highlight some of the negative impacts of delayed diagnosis of endometriosis. Since she was told that her symptoms did not matter as much because she had no intention to get pregnant, her physical needs to live pain-free were swept aside as insignificant because she did not have goals to reproduce. The impact of the doctor's dismissal was that Peyton felt less inclined to advocate for herself. It is worth reiterating the progressive nature of endometriosis. So, although she was approaching her doctor to say something was wrong with her menstrual cycle, the doctor did not see it as significant since there was no intent to get pregnant. Meanwhile, the disease continued to grow inside of her while left untreated. Then, when she moved to Washington and doctors decided to investigate why the intrauterine device (IUD) was not going in, they found a twelve-centimeter cyst that could have caused irreparable damage or a fatality. Peyton's experience is an important display of what is at risk when endo patients are dismissed. Not only does the dismissal of pain lead patients to feel less inclined to self-advocate, but untreated endometriosis continues to grow and can lead to permanent, and sometimes fatal, repercussions. As Peyton's experience reflects, not all people living with endometriosis who face dismissal by doctors feel empowered to self-advocate, which is concerning since their disease might result in life-altering effects.

Many medical practices claim their commitment to social justice, which suggests that all members of the medical encounter will be treated as equals. More often, there is an imbalance of power between the doctor and patient, in which doctors retain agency as experts on disease. Due to the power dynamics at play, self-advocacy in the context of endometriosis is often recognized as an accomplishment due to the barriers that patients face trying to engage their doctors in recognizing their needs. Drawing from the work of Patricia Hill Collins, I argue that doctors commit epistemic violence through silencing patients' reports of their health concerns.[176] The constant silencing that patients experience by their doctors who dismiss the patient's symptoms represent the impact of being silenced by people in power, teaching patients to self-censor and refrain from sharing their experiences candidly with their doctor.[177] Therefore, the gendered silencing of women is intensified through patterns of doctors' dismissal of endo symptoms. The process of patient self-advocacy is an active rejection of gendered roles to remain silent about menstruation. While many people with endo do learn to educate themselves and advocate for their health, others are left struggling with physical symptoms of an unnamed illness, and experience additional mental health symptoms as a result.

Delayed Diagnosis of Endometriosis and its Connection to Mental Health Issues

Their eventual diagnosis of endometriosis allowed the participants in this study to reflect on the mental and emotional toll of the disease. Throughout the interviews, participants shared

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[176] Patricia Hill Collins, "Intersectionality and Epistemic Injustice," in *The Routledge Handbook of Epistemic Injustice*, (New York: Routledge, 2017), 121.
[177] Collins, "Intersectionality and Epistemic Injustice," 121.

how the years spent living with undiagnosed endo taught them not to trust themselves or led them to develop mental health challenges because of the repeated dismissals by their doctors. Aligned with Whelan's findings through qualitative data collection, the emergence of mental health as a theme in my sample similarly indicates that many patients, "…admitted to questioning their own mental health when doctors delegitimated their suffering, especially before diagnosis when there was no explanation for it."[178] Endometriosis literature, such as Elanor Thom's *Private Parts*, suggests that "Endometriosis can have a huge impact on a person's emotional and mental well-being and this aspect is rarely given much attention."[179] However, the participants in my sample spoke often of the impact of endometriosis on emotional and mental health.

Throughout my interviews, it became apparent that one of the effects of living with undiagnosed endometriosis was an increase of mental health problems. Since those living with undiagnosed endometriosis faced chronic symptoms ranging from severe pain to fertility challenges, they struggled to manage their daily encounters with debilitating symptoms without a diagnosis. The frequent struggles with pain, heavy bleeding, or other unmanageable symptoms challenge those living with undiagnosed endometriosis because their doctors could not name their illness, leaving them to feel helpless. As a result, many of the participants in my sample shared examples of facing sadness, depression, or grief because of their experiences with endometriosis.

Participants in my sample shared examples of experiencing depression tied to threats of infertility. One reason that the cultural ideology associated with motherhood is so deeply

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[178] Whelan, "'No one agrees except for those of us who have it,'" 973.

[179] Eleanor Thom, *Private Parts: How to really live with endometriosis….* (Great Britain: Coronet, 2020 [2019]), 278.

entwined with endometriosis is because of the relationship between endometriosis and fertility. Endometriosis specialist Dr. Seckin says, “Endometriosis is the one disease with which fertility problems are most closely associated.”[180] It has been estimated that endometriosis is found in about 50 percent of people struggling with infertility.[181] Therefore, there is a scientific basis for the concerns surrounding endometriosis and fertility. However, it is worth clarifying that infertility is a symptom of only about 30-50 percent of people diagnosed with endometriosis.[182] So, although there is a correlation, endometriosis does not always lead to fertility issues. While the rate of endometriosis in folks struggling with fertility challenges is high, an endometriosis diagnosis does not necessarily mean that one cannot get pregnant, though this is a common cultural myth. As evidenced through my firsthand experiences, when I share with people that I have been diagnosed with endometriosis, their first reaction tends to be, “So you can’t get pregnant?” or “I’m sorry you can’t get pregnant,” which is not necessarily true. Uniquely, many people who struggle with fertility challenges often do not have other symptoms of endometriosis. Many people do not seek a diagnosis of their endometriosis until they try to conceive and face challenges. Silent endometriosis refers to endometriosis that is unaccompanied by severe symptoms such as pain and heavy bleeding but shows up in patients who struggle to conceive.[183] Although there is a connection between endometriosis and fertility, the presence of one does not guarantee the other.

Fertility challenges are a symptom of endometriosis and people living with endometriosis who face challenges while trying to conceive can find themselves facing feelings of depression.

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[180] Tamer Seckin, *The Doctor Will See You Now: Recognizing and Treating Endometriosis*, (Nashville, Tennessee: Turner, 2016), 61.

[181] Seckin, *The Doctor Will See You Now,* 62.

[182] Kerry-Ann Morris, *Living Well with Endometriosis: What Your Doctor Doesn’t Tell You… That You Need To Know,* (New York: HarperCollins, 2006), 77.

[183] Seckin, *The Doctor Will See You Now,* 61.

In our interview, Mia, a 38-year-old woman from Illinois expressed how she suffered from silent endometriosis, never noticing symptoms until she struggled to conceive. For Mia, the goal was to start a family, and when she struggled to get pregnant, she started in vitro fertilization (IVF):

> I mean, if you talk to anyone who's gone through IVF, or any of the other types of infertility, it's, it's all consuming. And, you know, my psychologist has shared with me that for women who are going to their first appointment with a reproductive endocrinologist at baseline- before they've had any of the tests or any of the procedures- at a baseline, they already screen you, give them a depression screener, they already are experiencing depression. So, then when you add in the failures, and you know, things worsening and things like that, it just serves to worsen you know? So, I think the depression on my part, you know, it pulled me under in a way that maybe some other women don't experience. Maybe some other women are better able to access their support systems for a long time. The only person I would talk about it with was my husband, and he's been an amazing support this entire time. But he is a man, and he is just one person. And you know, there's other things involved in a relationship besides like coping, you know? So, you know, it's been really, it's been really just again, it's just been amazing. Like, it's been a liberating experience to kind of get the diagnosis and be able to connect with the endometriosis community. And I have to say like, the infertility community has also been amazing. You know? It's not to say, you know that that hasn't been helpful. It has in so many ways. But I always felt like yeah, like the infertility was a symptom. And there had to be a reason like, why was this happening to me? What was causing this? Why would this happen? And there's nothing wrong with me. And so again, like this was the missing piece of the puzzle.

As Mia shares her struggle with depression that came because of her inability to conceive, she also helps us to see how approaching IVF comes with additional mental health challenges. Perhaps because of external pressure to conceive, or internal disappointment because of a sense of inadequacy when trying to get pregnant, Mia shares how the experience pulled her under. Although she spoke with a psychologist and relied on her husband for support, Mia then shares how it was with the endometriosis diagnosis and access to those communities that she started to come around and feel better seen and supported. She describes the validation of getting diagnosed with endometriosis as a missing piece of the puzzle that allowed her to better contextualize her situation. She felt bogged down with the question of why she could not get pregnant for so long that she faced depression while pursuing IVF. Once diagnosed, she felt she could better face the challenge because there was at least a clear name for the illness she needed to treat. Mia’s experience emphasizes the cost of delayed diagnosis, specifically the risks to family planning outcomes, when someone’s endometriosis goes undiagnosed. In Mia’s case, not knowing why she could not get pregnant led to depression and caused mental health challenges because of her physical illness. Distinct from the implications discussed in chapter one, in which I explain how doctors have historically suggested that people with endometriosis are merely struggling with mental health or making up symptoms in their mind, Mia’s case shows how the physical impact of endometriosis can lead to mental health issues due to the physical symptoms of the disease. Mia’s account represents how those seeking endometriosis diagnosis because of fertility challenges often experience mental health challenges related to the unknown cause of their inability to conceive.

The damages of living with undiagnosed endometriosis can escalate the effects of other mental health issues such as anxiety or feelings of grief. In our conversation, Raya, a 29-year-old from California shared that her endometriosis led to irreversible damage to other organs such as her bladder because of the endometriosis adhesions, sharing, “It could have been avoided, had I gotten, you know, an excision surgery, you know, ten years ago.” As mentioned earlier, endometriosis is progressive, so the delay to diagnosis can cause lasting impacts on those who are not diagnosed and treated in a timely manner. Raya added, “I think it's just kind of like frustrating, because so many women have this, and so many doctors are not educated about it that, you know, it shouldn't take this long, it shouldn't take this long at all for like, women to find out that they have it.” Unfortunately, it does take a long time for most people with endometriosis to be diagnosed, which does lead to long-term effects resulting from the overgrowth of endometrial tissue around other organs. The symptoms of endometriosis are disruptive and can get in the way of daily life, leaving the individual frustrated because of their inability to know what the long-term effects will be. Raya describes the mental anguish that comes from living with endometriosis, sharing that:

> I mean, there's definitely a sadness, like thinking about, like, all the things that I've missed, because I've had to like cancel plans, because I don't feel well. A sadness that, you know, I've developed fibromyalgia, most likely from this, which is going to be something I deal with for the rest of my life. And like no matter you know, if the endometriosis gets excised, and you know, even if I don't have an issue with that in the years, like, I'm still going to have this like chronic fatigue and all over body pain. I think there's, I think there's an anxiety that comes with it as well. Because it's hard to trust your body when you have all these different things happening. I'm always like, 'Is this a flare up? Am I dying? Do I need to go to the hospital?' And so you know, it creates this like medical trauma where you know, and I'm like, one of those people that watches a lot of like, True Crime stuff. So, it's like I've gone from like, being afraid that like someone's gonna break in my house and murder me because I watched too many true crime things to being like, 'No, my body is like, my body is my biggest threat it feels like.' And so, it's just like this constant like body anxiety and like exhaustion both physically and mentally. Like, whenever my period comes, I'm always like before, even like the pain starts when I just know what's coming, I'm already like, exhausted and sad and mad. And just like, I feel like I go through like the five stages of grief every time my period comes.

Raya's reflections on how endometriosis leads to different mental health responses outlines the sense of sadness that one faces when missing out on daily life due to physical illness and then shifts towards a discussion about how the unexpected symptoms of endometriosis can increase anxiety. Since the symptoms are unpredictable, often living with endometriosis results in anxiety because of the inability to plan or to know when symptoms will be debilitating. Due to her inability to trust her body, Raya shared that the fears she once had of external threats such as someone breaking into her home have been replaced by fears of how her body is going to feel on any given day. Further, in anticipation of her period, Raya shared that she moves through the stages of grief because of how impactful the experience of menstruation is. Examples like Raya's emphasize the connection between mind and body, demonstrating how the physical symptoms of endometriosis can have lasting impacts on one's mental health.

Other participants describe their experiences with grief due to living with endometriosis because of the impact it has had on their ability to participate in daily life. When discussing grief, other participants shared that it is a complicated feeling in relation to endometriosis because it is grief of something one has not had or experienced. The grief related to endometriosis is often related to the lack of experiencing a typical, healthy menstrual life. In our conversation, Zoe, a 34-year-old woman from Pennsylvania shared:

> I mean, grief is a big part of it. And I think you can't grieve what you never had. And so, in some ways, it's a little bit easier because I don't know any different. It is. In the same way that like, it's very easy to idealize. Like, it's, it's sort of like grass is always greener stuff that like, I have friends that like, like, I'll never forget the first time where a friend was like, 'Oh, I'm on my period.' And like, it wasn't like a two-week wind up. It wasn't like debilitating twenty-four hour pain. Like, it was just like, 'Oh, I went to the bathroom. And like, oh.' And I just remember, like, in that moment being like, 'Is that how it works for some people?' but like, 'This isn't something that you have a low-level awareness of most of the time, most days of the month?' Like, 'Seems cool.' But like, the most acute grief, though, was after I had surgery, and I was like, 'Oh,' because it reset my baseline in a way that I was profoundly sad. For not knowing enough to, like, advocate better, I'm like, I was in the top ten percent of people making an informed choice. Like I wasn't, I wasn't blindsided by any of it. And yet, I still didn't know any better. And like that part of it feels very shared and real, where I'm like, 'Okay, like you had all of the tools, and you still made it to the ripe old age of thirty-four before you were like, I deserve to not be in pain every day.' Like how many other people? And that part of it gets me really sad. Yeah, just grief.

Zoe emphasizes how even as someone making thoughtful decisions, she was not diagnosed until age thirty-four. For many people with endometriosis, there is a challenge to identify with people with healthy menstrual cycles because it is unimaginable that someone just goes through the month without focusing on how their menstruation will impact their choices and activities. After surgery, Zoe felt sadness because she had a new realization of how it felt to experience a typical menstrual cycle. She says that she did not understand that she needed to advocate for herself more and so she fell into the same pattern of other people with endometriosis whose diagnosis was delayed. What Zoe's experience demonstrates is that although people with endometriosis might recognize that their menstruation is different than others, there can remain barriers to accessing diagnosis because of a variety of reasons. Perhaps, due to the cultural messaging of menstrual pain as normal or the dismissal by doctors when one first shares their symptoms, people with endometriosis often suffer debilitating pain for years before getting proper diagnosis and treatment. Although those aware of endometriosis expect symptoms such as pain or fertility challenges, often the process of grief is overlooked as a side effect of endometriosis. Paying more attention to the experiences of people with endometriosis will allow for treatment that encompasses their whole experience.

If endo is more widely discussed and general awareness about the disease increases, perhaps people suffering from endo would feel better prepared with the tools necessary for articulating their experience and demanding treatment. If endo warriors were prepared to advocate for their health earlier, perhaps they could avoid spending decades suffering, like Kylie, the 41-year-old from North Carolina whose diagnosis took twenty-four years. Kylie shared how endo makes her sad for all the things she missed because of being sick. Kylie said, "I spent two-thirds of my menstruating life suffering for a week every month, except for the three and a half years I was pregnant and breast feeding." The twenty-four years it took Kylie to get diagnosed with endometriosis were filled with symptoms and challenges that led to cancelled plans or stress because of not knowing why she was suffering. Kylie said, "I guess I'm kind of grieving the missed time and all the anxiety I had. I'm just really upset that because people didn't believe me at a young age that I just had so much anxiety about it." Kylie's experience represents the entanglement of what impact delayed diagnosis can have on people with endometriosis's mental health and the resulting grief. Since she struggled for so long without answers, Kylie now faces grief for all the lost time and missed opportunities that are results of her experience with delayed diagnosis of endometriosis.

Like the resulting grief experienced by Raya, Kylie, and Zoe, another participant shared descriptions of some of the emotional toll endometriosis has taken. Kendall, a 30-year-old woman from Massachusetts explains that her experience with endometriosis led to sadness. She adds, “Also you’re kind of angry, just because of not being believed for so long. Yeah, I guess I'm like you know, ‘What, if it had been diagnosed earlier, or?’ I don't know, I just wish that… it just pisses me off that they didn't believe me.” Since doctors did not believe Kendall, it took four years to be diagnosed. She questions why doctors did not listen to her reports of symptoms and adds, “I know my body. Yeah. Yeah, so I guess it just kind of just kind of sad and just, like, makes me feel like, my body like turned against me.” The sensation that one’s body is working against them is common throughout my conversations with people living with endometriosis. As reported by the participants, since one’s body is inescapable, it becomes difficult to navigate daily life when one’s body is not functioning properly. When the symptoms associated with endo pop-up out of nowhere, it can be challenging because it feels like one cannot trust their body and the relationship to their body becomes one of fearful anticipation. The daily mix of symptoms one can endure from endometriosis can make it difficult to plan activities confidently. There is a common sense of uncertainty reported by participants regarding their relationship to their bodies and whether endo symptoms will disrupt their plans unexpectedly.

The sensation that one’s body has turned against them, and the resulting sense of sadness better contextualizes why the delayed diagnosis of endometriosis is significant to the one in ten people with internal reproductive anatomy who are afflicted. As noted in the examples above, the delayed diagnosis can result in irreversible damage to organs, but it can also lead those who finally reach a diagnosis to mourn or grieve because once they are diagnosed and treated, they start to recognize the profound impacts that endometriosis has had on years of their lives. The themes of mental health from my sample align with findings by Whelan, who said, “While the participants denied that the symptoms of endometriosis were caused by psychological dysfunction, they did point to several ways in which psychological dysfunction may result from endometriosis.”[184] In the following section, I highlight what the people with endometriosis from my sample had to share about what getting diagnosed meant for them in relationship to their mental health and how the diagnosis made them feel.

Diagnostic Validation: You Were Right, Endometriosis is Real

As I have discussed, people with endometriosis often rely on themselves to learn about the disease to advocate for their healthcare outcomes. Moreover, the experiences of living with undiagnosed endometriosis often contribute to mental health challenges. In this section, I highlight examples from the interviews in which participants reflect on the process of receiving a diagnosis. Many participants from my sample discussed the impact of receiving a diagnosis as fundamental in their recovery process. In our interviews, participants such as Sophia share the impact of learning that their symptoms have an explanation. Sophia said, “…having a diagnosis means I’m not crazy.” Learning that the unexplained symptoms she had been managing for twenty years was because of an underlying disease, Sophia shares a sense of relief that she could trust herself even if she didn’t feel she could trust her body because she realized, “It’s not all in your head.” Since there is such a reliance on medical practitioners to explain what is wrong when we suffer from symptoms, there can be a sense of losing one’s mind when the symptoms reported are met with dismissal.

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[184] Whelan, “‘No one agrees except for those of us who have it,’” 973.

The theme of diagnosis validating the experiences of participants and making them feel relief that they were right that something was wrong came up frequently in my sample. Connie, a 26-year-old woman from Washington had a three-year track to diagnosis, but shared similar reflections:

> I actually felt heard. I felt like validated. Actually, I did. I thought I was going crazy for a second. I was like ‘At this point, I'm just making this stuff up.’ And you know, ‘Nobody can find anything.’ So, I was like really, really losing my mind. And when he actually confirmed everything with the tests that he performed and all that stuff that he did, I felt like a peace, like I could actually take a breath.

Other participants from my sample shared a similar sense of calm that washed over them once they received a diagnosis of endometriosis, which validated their suffering. The tension of feeling as though they were somehow creating the problem in their mind and then realizing that what they felt had an explanation deep beneath the physical surface of their skin provided many folks with a sense of relief. However, not everyone felt so positive about the news. For example, Charlie, a 28-year-old from Vermont reported feeling overwhelmed by the diagnosis. Charlie recounts the mixed feelings of learning that her doctors did find endometriosis:

> They did find it. I was a little overwhelmed though because they found it. Like I said, they found in on my diaphragm. They found it over my bladder, they found it on both my ovaries. I had cysts on both my ovaries. They found it on both ligaments, the uterus, sacral ligaments, the cul-de-sac, under my colon, pelvic sidewall- everywhere. They took my appendix out. Everything was stuck to everything. So, they had to cut all the adhesions and all of that. So, there was just so much done. It was like, “Holy crap!” But it was also validating.

Charlie’s response to learning that the doctors found endometriosis in many places was met with more hesitation than some of the other participants shared. Yes, Charlie felt validated by the diagnosis, but also, she reports the sense of surprise she felt because of how much the disease had spread throughout her body. For Charlie, like so many, a diagnosis was just the start of a new health journey. Although learning that one has endometriosis is a necessary step towards healing, due to the seventeen years it took for Charlie to finally get a diagnosis, the disease had progressed to stage four and done a lot of damage. Staging of endometriosis is determined by three factors, 1) the amount of endometriosis present; 2) the location of the endometriosis; 3) the severity of the disease.[185] When endometriosis reaches stage four, it can bind organs together or restrict organ function, causing irreparable damage.

An example from my conversation with Mia, the 38-year-old woman from earlier in the chapter who lived with silent endometriosis and sought care when struggling with fertility, provides a typical unravelling of how the link between diagnosis and validation might be interpreted by the patient:

> There's frustration for sure. Um, but I also feel I'm really seen and heard by other women in the endometriosis community, I think my story is, in some respects, all too common, and everyone has their own unique story, but there are parallels and one of the parallels I've come to learn is having doctors give you the wrong information or to dismiss you. So you know, feeling like you know, having gotten this diagnosis, like I feel validated because you know, I had done a lot of self-education, right, everything I could get my hands on from Nancy's Nook and you know, really developed a deeper understanding about the disease and became more and more convinced, you know, until finally, like, I found a doctor who would just go ahead and do the surgery, you know, so I feel validated that, you know, essentially like, I knew somewhere deep down inside—and that was actually the first thing my husband said after we got off the phone with a surgeon she called us after we got home because she had to go after my surgery to another one. So, when we got off the phone with her, you know, I just kind of sat silently like letting it soak in that I had stage four endo. And he, he said the first thing he said was, 'You knew it all along.' And, you know, it was interesting because the morning of my surgery, I woke up with this kind of mixture of anxiety and almost guilt. Because I felt like I was going to waste everyone's time, you know, because I didn't have severe pain because I didn't have a lot of doctors backing me up saying, 'Yeah, give a lap.' It was really something that I was driving. So, I felt like, I was gonna wake up from surgery, and they were going to tell me nothing was wrong. So, it's interesting, you know, I did feel validated.

Although Mia's diagnosis took four years, which is shorter than the average, it still took too long. Since Mia's goals were to get pregnant, the four years it took to be diagnosed, from age

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[185] Revised American Society for Reproductive Medicine classification of endometriosis: 1996. *Fertil Steril.* 1997;67:817–21.

thirty-four to thirty-eight, posed real consequences in the scope of her reproductive goals. Mia's comments also highlight how it was not until she became self-educated and learned enough to suspect endometriosis that she was able to approach her doctor and share that she wanted surgery to determine whether endometriosis was present. She had to advocate for herself and propose the diagnosis, and once doctors agreed, they found that she had stage four endometriosis, which is the most advanced stage of the disease. In Mia's case, her stage four endometriosis had progressed to the point that it caused fertility challenges. Although she had a hunch that it was endometriosis going into surgery, Mia reports feeling uneasy about whether they would find anything. Mia's story corroborates that of many others from the sample who explicitly note the effect of dismissal or being misled by doctors as a factor in the delayed diagnosis of their disease.

As shown in the examples, the process of diagnosis is a becoming, through which people who spent years without answers for their suffering discover a reason behind their struggle. Although learning that they have endometriosis is a starting point in the process of treatment, the validation that their symptoms have a cause helps people who lived for years without diagnosis to feel recognized and validated that their experiences were real.

Endometriosis Interviews as Site of Epistemic Justice

The centrality of participant interviews throughout this chapter are representative of how my work is a manifestation of epistemic justice. Throughout the chapter, I addressed how doctors have rejected the reports of their patients' menstrual-related symptoms, which, as the participants in my study report, leads patients to take their diagnosis into their own hands by engaging with additional educational resources in their search for diagnosis. I argue that self-education and self-advocacy are an important aspect of patient participation in the search for endometriosis diagnosis, which challenge the underlying sexist medical ideologies that assume women exaggerate their symptoms. Further, endometriosis can lead to psychological symptoms that extend beyond the physical strife of pain or fertility challenges. Mental health symptoms can manifest as depression, anxiety, and feelings of grief that result from the medical dismissal that the participants encountered. Receiving a diagnosis leads endometriosis patients to feelings of validation. Patterns of doctors dismissing patient accounts of menstrual pain is an epistemic injustice, in which doctors do not consider patient reports to be reliable. The centering of firsthand accounts by people with endometriosis featured throughout this chapter is an effort towards epistemic justice, in which patient narratives are deemed as valuable and medically accurate data.

Throughout this chapter, I have presented themes from the interview data that represent the role of self-education, and self-advocacy in the context of endometriosis delayed diagnosis. For many people living with undiagnosed endometriosis, the constant dismissal by their doctors creates distrust that leads them to start searching for answers on their own. Participants in my study reported how they self-educated to deepen their understanding of endometriosis and that once they felt more aware of the disease and its impact, they felt empowered to self-advocate. Breaking from traditional gendered expectations of remaining silent about their menstrual-related symptoms, many participants in my study attribute their eventual diagnosis with advocating for their health in the face of dismissive healthcare providers.

Additionally, this chapter has provided an examination of the relationship between endometriosis, mental health, and diagnostic validation. Since endometriosis symptoms vary from deep pain to fertility challenges, the unique experiences of each person with endo is individualized. However, despite which symptoms they face, it is common for people with endometriosis to additionally experience mental health challenges because of the delayed diagnosis. The participants in my study report how living with unexplained symptoms for years contributes to anxiety, depression, and feelings of grief, especially in the face of doctors who dismiss the concerns brought forth by patients. In this chapter, I highlighted examples from the participant interviews in which they described the experience of being diagnosed and the resulting validation. I share these examples to demonstrate the impact of delayed diagnosis, through which people living with endometriosis face an onslaught of mental health challenges because of their inexplicable symptoms. Then, once they realize that their symptoms have an underlying cause, they often have a sense of contradictory feeling of relief and grief, with excitement that they can seek treatment and sense of regret for the years they spent suffering.

The mixed messages about mental health challenges associated with living with undiagnosed endometriosis can feel overwhelming while folks seek answers. The dismissal of patient reports of symptoms related to endometriosis within medical appointments displays an example of "willful hermeneutical ignorance," an epistemic injustice in which dominantly positioned doctor explicitly disregards the knowledge-making tools of their marginalized patient.[186] In the doctor-patient relationship, doctors engage in willful hermeneutical ignorance by avoiding patient accounts as serious contributions to medical knowledge production. Since doctors are valued as authority figures, whereas patients are rendered powerless, patient knowledge is undervalued and often explicitly disregarded. Pohlhaus Jr. describes willful hermeneutical ignorance as, "the knower's continued engagement in the world while refusing to learn to use epistemic resources developed from marginalized situatedness."[187] The result is that

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[186] Gaile Pohlhaus Jr., "Relational Knowing and Epistemic Injustice: Toward a Theory of 'Willful Hermeneutical Ignorance,'" (*Hypatia* 27, no. 4, 2012), 715.

[187] Pohlhaus Jr., "Relational Knowing and Epistemic Injustice," 722.

the dominantly positioned knower, in this case doctors, cannot understand the violence they have perpetuated in their refusal to integrate patients into the process of knowledge production. Limited medical background might leave patients with less scientific means for discussing their experiences, but doctors should be flexible to hear what patients have to say and try to bridge the gap between those reports and the available medical interventions. Doctors tend to rely on the medically established knowledge, even if patients provide alternative information derived of their personal research or experiences, foreclosing the potential contributions by patients towards production of new knowledge.

Doctors' willful hermeneutical ignorance, through which they suggest that nothing is physically wrong with the patient who consistently reports endometriosis symptoms, can create a sensation for the patient that they are not mentally well, as they feel phantom pains without explanation. It is disorienting to be interrupted by excruciating pain while participating in daily activities. Feeling terrible while there is no visible indicator of illness to the outside world further complicates such experiences. Since endometriosis has such a plethora of symptoms related to it, a commonly reported impact of living with the illness is mental health problems. Specifically, for those searching for a diagnosis to no avail for the average ten-years it reportedly takes, those years can weigh heavy on their mental health. Therefore, the many symptoms of endometriosis can lead to mental health challenges as a side effect of the condition, as the participants in my sample shared through multiple examples. Importantly, upon diagnosis, many of the participants in my study shared the overpowering sense of validation as a result. There is a connection between the mental health issues faced while living with undiagnosed endometriosis, and the impact of diagnosis. Specifically, the confirmation of an endometriosis diagnosis allowed those from my sample to feel relief and finally truly believe that they were not exaggerating their symptoms or that their symptoms were "all in their head." Rather, their diagnosis was both a step towards healing from the physical symptoms of endometriosis, but also the mental health symptoms suffered as an additional side effect of their undiagnosed illness.

The discrediting of patient accounts is an example of epistemic injustice in which testimonials are considered anecdotes rather than knowledge. However, valuing firsthand accounts by marginally oppressed patients, such as those living with endometriosis, can help to identify reasons for diagnostic delay. Speaking with people living with endometriosis helped to uncover the themes across their experiences that indicate how epistemic injustice has led patients to self-educate and advocate. As I have demonstrated throughout this chapter, patient narratives are valuable in medical education and paying attention to patient narratives is important to progress clinical practice.[188] Therefore, previously dismissed sites for knowledge production such as patients expressing themselves through narrative are starting to gain traction as legitimate forms of expression.[189] Recent medical humanities scholarship suggests that, "medical knowledge is narratively structured," and that, "doctors learn to diagnose and treat from repeated exposure to patients' stories, thinking narratively."[190] However, in the case of endometriosis, trends of delayed diagnosis due to patient dismissals indicate that patient accounts are not yet receiving adequate attention from medical practitioners. This chapter is an attempt to press medical practitioners to value their patients' knowledge of their symptoms and to seek answers when a diagnosis is not immediately obvious. Additionally, this chapter is an effort to provide narrative examples of firsthand accounts of people living with endometriosis to give

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[188] Carel and Kidd, "Epistemic Injustice in Medicine and Healthcare," 344.
[189] Carel and Kidd, "Epistemic Injustice in Medicine and Healthcare," 342.
[190] Alan Bleakley, *Medical Humanities and Medical Education: How the medical humanities can shape better doctors*, (New York: Routledge, 2015) 18.

others seeking an endometriosis diagnosis validation that the challenges they may be facing are not theirs alone.

Through firsthand endometriosis patient accounts, it becomes clear that the lacking epistemic agency results in epistemic oppression of patients as authority-bearing individuals. Epistemic oppression provides a theoretical approach to unpacking the power dynamics that privilege the knowledge of doctors as authorities in the lives of endometriosis patients. Although they likely know their body and health experiences better than anyone, dismissal of patients by doctors is persistent. Collins outlines the dynamics present in epistemological relations, "Epistemic oppression suppresses the epistemic agency of some members of the group while elevating that of others, thus producing privileged and derogated categories of knowers."[191] As we see in medicine, there is an assumption that doctors and physicians hold the epistemic agency and thus, patients are discredited from the medical community as knowers. This project disrupts patterns of holding doctors' knowledge to a higher standard than their patients, and I challenge patients and doctors alike to recognize the value of patients' descriptions of their experiences and symptoms in the process of diagnosis.

In the following chapter, I depart from the interviews and deepen my engagement with centering the voices of people living with endometriosis as experts by sharing a purely autoethnographic chapter recounting my personal experience with endometriosis. In the following chapter, I position myself as an expert, not explicitly through the research I have done on the topic, but as a person who has faced a firsthand experience with delayed diagnosis of endometriosis.

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[191] Collins, "Intersectionality and Epistemic Injustice," 120.

Chapter 4: Endometriosis: Reflections on Reclaiming My Health

Endo Belly

I learned how to
Hate my body
Long before I desired
To love my body.
A preteen with
A bulging abdomen
Surrounded by judgment,
I learned to never
Give myself the breath
My lungs desperately craved,
Lest my core expand
Beyond my control.
There is a constant
Reframing process
Happening in my mind,
Even as I scan my body
For any looming threats.
We are at war;
I have to remind myself
We are on the same side.[192]

From Firsthand Experience to Dissertation Research

The endometriosis diagnosis I received during my gap-year between master's and doctoral study changed the trajectory of my research. My experience with a real-life issue that impacts 200 million people worldwide led me to reevaluate what I wanted to spend my time investigating. Although endometriosis impacts so many, time and again, when I mention the term 'endometriosis,' people ask me, "What does that mean?"

My experiences as a member of the endometriosis community provided me with insights into the layered complexity of living with endometriosis. Since endometriosis is so deeply entangled in notions of womanhood, investigating endometriosis experiences provides a critical

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[192] Maggie Bowyer, *When I Bleed: Poems about Endometriosis*, (Greensboro, North Carolina: Margaret Bowyer, 2021), 83.

case study for understanding the intersections of gender and medicine. Truthfully, like so many living with endometriosis, I probably would never have taken such an interest in the topic, had it not caused such damages to my health for years. After I received a diagnosis through a surgical treatment that did not help me to feel relief, I started to learn more about the patterns of medical dismissal, delayed diagnosis, and medical sexism that contribute to countless stories of people suffering with untreated endometriosis for years. Today, I write from a space of having endured endometriosis delayed diagnosis. My story is that of a twenty-something-White-middle-class-cis woman, which has privileged me in ways that have supported my journey to relief from endo symptoms. Due to my positionality, in addition to receiving a diagnosis, I eventually was treated with the gold standard of endometriosis care. Although my story of delayed diagnosis is all too common, the opportunity to get treated *and* experience relief after an eleven-year delayed diagnosis is not common amongst the folks I interviewed.

Having had a deep excision surgery, an expensive and almost exclusively out-of-pocket private surgery in 2021, today I live mostly pain free. The chronic pain that once tormented me has been replaced by the freedom to exercise, enjoy sex, and make plans without fear that I will not feel well enough to participate. Although my periods used to last for weeks on end with spotting in between, I now typically bleed for about four to five days. My cycle length is about thirty-one days, well within the average span of a healthy cycle. While I still experience some cramping or pain during ovulation and the first two days of bleeding, it is nothing compared to the agonizing slashing sensations I once faced on a regular basis. My life has been transformed, and I am convinced that with early intervention and specialized care, the one in ten people with internal reproductive anatomy living with endometriosis could similarly find relief. Approaching surgery, I said that even one more pain-free day a month would make it worth it. One and a half years post-surgery, I experience few endo symptoms. Receiving adequate treatment has allowed me to regain my strength and revisit my passions from hiking in the back woods behind my home to trying to cook new recipes. Now that I am not in chronic pain, I can participate in the activities that used to bring me joy. The delayed diagnosis of endometriosis is inexcusable given the advanced technology available to visualize abnormal endometrial growths. Further, inefficient treatment of endometriosis is widely performed despite the availability of more effective alternatives.

As I reflect on my experiences with endometriosis, I am saddened. Something like survivor's guilt washes over me because although my story with delayed diagnosis is all too common, my experience getting proper care and feeling better after years of suffering from endometriosis is somewhat of a fairytale ending. Many of the people I interviewed, although diagnosed with endometriosis, are still in active pursuit of relief from their endometriosis symptoms. Some participants continue searching for treatment to reduce their pain and other symptoms, something I have been privileged to achieve. Other participants continue in their efforts to get pregnant, using assisted reproductive technologies due to their inability to conceive naturally because of late-stage endo. Importantly, although this research has outlined the damages of delayed diagnosis to people living with endometriosis, the diagnosis is just the starting point, as my experiences having had two surgeries will show.

My Journey with Endometriosis

I struggled for eleven years with severe pain and irregular periods before getting diagnosed with endometriosis. Every time I mentioned my menstrual symptoms to my doctor, the conversation was over quicker than it began. They told me it was "normal," or "nothing to worry about." I had no idea that the distress I suffered because of my menstruation was indicative of a progressive disease. Like so many others living with endometriosis, I just accepted that I was one of the unlucky ones whose periods were bad.

Since I started menstruating at age twelve, my periods got progressively worse. I always suffered from irregular and painful periods. My bleeding lasted longer than my friends' and the time between bleeding was much shorter. During the worst of my teenage years and early twenties, my periods were so irregular that I would bleed for ten to fourteen days straight, often with a moderate to heavy flow. I would then stop bleeding for about fourteen days before the cycle repeated. What I experienced was not like anyone I knew. None of my friends described the things I went through. I was extremely frustrated and received the generic feedback from my family doctor that, "some women just have worse periods." I had never heard someone else say that they bled for half of the month, every month. However, since my doctor said I was okay, I did my best to just ignore the inconvenience of it all. The doctor said it was fine, so I believed them.

Every appointment, I persistently shared my symptoms with the doctor. They would ask, "How have you been feeling?" and I would say something along the lines of, "Just the same complaints, my periods torment me, but otherwise I am well." Eventually, around age fifteen I tried birth control after my doctor recommended that it could help me to "regulate" my period. Over the years, I tried numerous birth control pills and even when they seemed to work for a month or two, eventually I would have breakthrough bleeding after three or four months of use. The breakthrough bleeding would eventually put me back into my same old pattern, in which I was bleeding half of the time.

I went through so many pads and tampons that I could not estimate the number or cost. For half of the month every month, I used tampons during the day and pads at night while I slept.

When my flow was heavy, I wore a pad and tampon to avoid bleeding through. I kept backup menstruation management products everywhere. They were shoved in every purse and coat pocket, in my locker at school and the center console of my car, and I even kept a backup stash in a drawer at work because I never knew when I would start to bleed or need another pad or tampon.

In high school, I quit the field hockey team mid-season because my menstruation felt unmanageable. In addition to the challenges of bleeding so frequently, the constant periods led me to suffer from cramps and fatigue. I was constantly drained of my energy, feeling completely challenged to continue my daily tasks, never mind compete in such a physically demanding sport. At the time, I felt a lot of guilt quitting the team. I felt like I was letting my coach and the team down. I was too embarrassed to tell the coach that I was quitting because of my menstruation, though I suspect my mom might have called to explain it to her separately. Now, after having received a diagnosis for endometriosis, I can better contextualize what I was going through during my sophomore year and now recognize that quitting field hockey was not a sign of weakness, but a sign of the impact that my disease was having on my ability to partake in my passions.

I tried countless birth control pills between the ages of fifteen and twenty-years-old. All the while, the bleeding was never managed, and I started to experience negative side effects associated with the hormonal medications such as weight gain, mood swings, anxiety, depression, and vaginal dryness. In my mid-teens during a doctor’s appointment, I told the physician that before menstruation I suffered from increased anxiety. Without further questions or examination, the doctor wrote me a prescription for Prozac and told me to take it as needed. I never filled the prescription, because it felt odd to me that the doctor did not even ask me a single follow-up question, nor did they tell me any potential side effects associated with the medication. Although I spent years complaining about my periods before being prescribed birth control, I only had to mention anxiety once for the doctor to write me a prescription. I never took the anxiety meds, and after years of trying different birth control pills to "regulate" my period symptoms, I stopped birth control around age twenty because I was sick of the side effects.

When I started dating my current partner at twenty-two-years-old, I decided to use birth control again to prevent pregnancy. I had such awful experiences using hormonal birth control that I decided to try a non-hormonal intrauterine device (IUD), the Paragard. I had the Paragard inserted in July of 2017. The concept of an IUD insertion totally terrified me. It was hard to accept that a small piece of copper would be sitting in my uterus for up to ten years. At the appointment, I cried and cowered in anguish as they inserted the device. With the IUD, my periods became even more painful and heavier than before. I had agonizing cramps throughout the month. I started to experience deep shock waves of pain during or after intimacy with my partner.

During the summer of 2018, I was waitressing at the diner I had served at all throughout high school. In one conversation with a coworker, she told me that the symptoms I described sounded like her daughter. She was the first person to ever speak the word "endometriosis" to me. Once she told me that it sounded like endometriosis, I did what anyone would—I Googled it. The symptoms I experienced aligned with what I was reading. I went to see my primary care physician so I could get a referral to a reproductive surgeon. When I met with the surgeon, he never suggested removing my IUD. Rather, he sent me for some tests including an ultrasound and some blood tests to conclude that surgery was the best option. The surgeon explained that with endometriosis, they basically rule everything else out before performing surgery to see if there is endometriosis growing around the reproductive organs. Although the surgeon did diagnose me with endometriosis, I want to note that the reproductive surgeon never recommended removing the IUD. The surgeon’s lack of concern about the Paraguard is surprising in retrospect because the Paraguard is known for causing cramping and heavy menstrual flow. Thus, once I learned the common side effects of the Paraguard through my research, I was shocked that the doctor never thought to remove it.

Leading up to my first laparoscopic surgery, during which a surgeon inserts a small camera to view the inside of the abdomen to identify and treat endometriosis lesions, the pain was so bad that I would throw up. I would crouch in a ball behind the counter and groan while working at the diner. I would choke back tears and put on a happy face while enduring pain that I can only describe as feeling as though someone was scraping my insides with a scalpel. The pain was piercing and abrupt, throbbing and aching, unexpected and inconsistent in nature, but the pain was persistent. Despite my drive and strong work ethic, I could not manage my daily obligations while enduring the challenges of the consistent pain. I could not wait for surgery. I was so excited to feel better. In October 2018, I went to the hospital in Massachusetts to have my first laparoscopic surgery. Right before the surgery, I was scared that when they operated, the surgeon would not find anything wrong with me. The procedure took about two hours, and I was released from the hospital on the same day.

Laparoscopic Surgery #1: They Finally Believe Me - Accepting the First Surgery I Was Offered

In 2018, I had my first laparoscopic surgery to diagnose and treat endometriosis, or so I was told. Leading up to surgery, I probably did a typical amount of research for someone going through this situation. I Googled here and there, read through some forums, and trusted that my doctor was going to “fix me.”

Going to the hospital, I was incredibly nervous. My thoughts were racing with anxiety. *What if they don't find anything? What if I do not feel better afterwards? What if the endometriosis is stage four? What if I lose my reproductive organs due to the damage? What if all my symptoms are just in my head?* I was terrified. Once I was dressed in my surgical gown, the members of the care team filtered in and out of the room to introduce themselves and confirm what operation I was there to have performed. I remember rolling into the hallway in preparation for surgery, the care team told me, "Here comes a nice cocktail!" and they administered intravenous medication to ease me into an unconscious state. When I awoke, a post-operative nurse greeted me to let me know I was okay. The anesthesia made me emotional, and I cried. My stomach was swollen from the gas that they filled me with to see inside of my abdomen. I felt tired and sore, but they told me they found endometriosis, which brought me deep relief and validation.

The surgeon had convinced me that doing a Firefly robotically assisted procedure was the leading treatment for endometriosis, and I trusted his expertise. I still have three visible scars on my abdomen, two to the left of my bellybutton and one to the right, physical reminders of the feigned hope that the first surgeon cultivated in me. I knew I was going in for surgery, but the surgeon did not prepare me for the scars that would permanently alter the appearance of my skin. It felt like he could have done more to prepare me for what surgery meant, both internally and externally. Sometimes I wish I had a before photo, just to remember the smoothness of my youthful tummy. The scars are quite visible, permanent reminders of the experiences I endured for years with endometriosis. The surgeon's encouragement to opt-in to using the Firefly Robot during surgery meant larger scars, something I was not advised about. Now I feel like I was misled, though I had no idea at the time. I agreed to the Firefly because he said it would help to find endo that he might not notice with his own eyes. Three years later, the expert surgeons in New York would teach me that the robotic surgeries often miss endometrial lesions because a surgeon is unable to feel the depth of the growth through the robotic assistance.

During the post-op appointment, my doctor did not say too much except that he found endometriosis and removed tissue that accumulated to about the size of a quarter. He said a paratubal cyst was removed and he described the endo as a mild amount and stage one. Later, in my post-op appointment with the doctor he said, “I expect you will need another surgery in one or two years.” I was shaken. I was absolutely dumbfounded. I thought getting treatment would put an end to my suffering, but it was just another bump in the road. Prior to the operation, the surgeon never gave any indication that this surgery was just a band-aid or starting point. When I was first told that surgery was an option, there was no indication that it would only provide relief for a year or two. There was no warning that this would be the start of a series of surgeries. I did not know what to do. Although this surgeon did listen and agreed to operate on me, something was not right. The doctor never presented the possibility of follow-up surgeries, never mind that they were an expectation. I left that appointment and never went back. I started researching endometriosis everything, and it became an obsession to learn more about how this could have happened to me. *How could this be happening to me?*

Following the post-op appointment with the surgeon, I was researching endometriosis in my spare time. I started to learn more about the significance of my symptoms related to endometriosis and took stock of how what I was reading aligned with my experiences. I learned learn more about the nature of the disease as an inflammatory illness, which explained why my symptoms worsened with the Paragard. I read information from organizations centered around endometriosis awareness such as the Endometriosis Foundation of America, and I created an account on MyEndometriosisTeam, where I could connect with others living with endometriosis. Through my research, I started to learn a bit more about how some of the more nuanced symptoms I had experienced could be attributed to endometriosis.

Worse than the realization that I would probably require a follow-up surgery, after weeks and months of recovery, I did not feel any substantial relief. After my first endometriosis laparoscopy, I did not feel better. The pain that led me to the procedure in the first place lingered, and I wondered why it was taking so long to recover. I rationalized that perhaps the healing process was slower than I expected. When months turned to years, I was depressed and shifted into a state of denial. Unable to face the fact that the worsening symptoms were residual endometriosis, I stopped using my period tracker or recording symptoms. I felt disturbed that after taking the leap and getting surgery, it felt as though I was back to square one. My first surgery did not fix me, as I had hoped. In some ways, it caused me further damages along my journey.

Purgatory: Post-Operative Distress and Denial

After about four months of healing, in January 2019, I recognized that the symptoms that led me to surgery persisted. I started to use a period tracker to track my bleeding in February 2019 and I was bleeding or spotting eighteen days out of the month. March, April, May, and June 2019 were comprised of lots of bleeding, pain, and frustration. I was so frustrated with my lingering symptoms that I decided to try hormones one more time. I went back to my primary care doctor in June 2019, and she removed the Paragard IUD and inserted the Mirena IUD.

The Mirena reduced the bleeding to shorter, lighter periods, but I still had pain. I also experienced negative side effects that had led me to stop using hormones previously, such as vaginal dryness, mood swings, depression, and weight gain. My breasts grew a cup size from the

Mirena and it hurt to do my workouts because of my newly sprouted C cups. I truly tried to like the Mirena. It was nice not bleeding as much. However, the side effects, including severe pain with sex, led me to finally remove the Mirena in February 2020. At the time, I had relocated for school and was living in California. I went to Planned Parenthood to have my IUD removed because I was in agony. It cost me $200 out of pocket because I had no health insurance in California. I wanted to see my baseline. I had to know if my pain was from the IUD or from residual endo. After the removal of the Mirena, I noticed that some of the pain symptoms I had been experiencing while exercising subsided, but my pelvic pain, my back pain, and the lateral pain on my lower left abdomen did not go away. All the while, I was managing the mental health challenges of trying to cope with chronic pain after having an effective surgery meant to heal it.

Facing ongoing symptoms, I continued to research endometriosis while working on my PhD at Claremont Graduate University. Although I became enthralled in the bigger picture of how culture was influencing the experiences of people living with endometriosis, I became disengaged from my own symptoms while pushing through daily obligations. I showed up for classes and work no matter what. I smiled my way through and never let on that I was struggling to stand upright or holding back tears because of the pain. I hid my suffering to avoid sympathy from others. I knew what was happening, so why bother others with my personal problems? I did not have California health insurance, so there was nothing I could do about it at the time anyway. I was in a purgatory state of denial that after having surgery, I was suffering. Of course, I knew that I was still facing symptoms, but I avoided them as much as I could. I disassociated from my body when the pain was severe. I stopped tracking my symptoms in my period tracking app. Adopting the coping mechanism of performing wellness, I hid my symptoms from others and pushed them aside, showing up for my obligations no matter what. All the while, I was afraid because I knew another surgery was on the table, but I did not know who, how, or when it would be possible to pursue further treatment.

Self-Education and Pursuing Deep Excision Surgery

When I relocated back to Massachusetts unexpectedly in July 2020 due to the Covid-19 pandemic, I continued the PhD program at Claremont Graduate University remotely. Spending more time at home, I started to recognize how frequently I reached for the heating pad, how often sex was painful or that I was afraid to have sex because of my fear that it would end with me in pain. The pain in my lower left abdomen would come and go for hours every day or two. Additionally, my bowel symptoms had worsened. I went through phases of diarrhea and constipation throughout my cycle. The irritable bowel syndrome-like symptoms were inconsistent and uncomfortable. I would go from feeling good about my flat tummy to bloated to the point that I looked pregnant in just minutes. Since I was home, I could make myself comfortable on the couch with a heating pad or turn off my camera in Zoom meetings when I was feeling unwell. Regardless, the symptoms were getting worse and more frequent. It was difficult to deny that I was debilitated by the endometriosis.

I was fatigued to a point that made it hard to do anything. I would lie down and rest in the middle of the day when I should have been working or doing schoolwork. My periods were painful, but my periods had always been painful. It was hard to evaluate the severity of my pain because I was so used to pain that it did not phase me until it reached an eleven out of ten on the pain scale and I could not move. I told people that at its worst, I was in pain that I can only guess felt like labor. I was sure that if I had not been previously diagnosed with endo, I would have gone to the emergency room when the pain felt like an eleven out of ten on the pain scale. Unfortunately, I knew that they probably would not have anything useful to offer me. My expectation with the first surgery was that I would feel better and I was disappointed when I continued to feel awful most days. For a while I held onto the hope that it was just a long healing process. Then, two years post-surgery, immersed in doctoral research on endometriosis, I realized that perhaps the methods or accuracy of the procedure I had done were not ideal. It took me some time to accept it, but I decided to find an expert who knew what they were dealing with to help me achieve treatment that would allow me to manage the pain.

My symptoms were worsening, and it became difficult to be intimate with my partner. Although sex had not always been painful for me, over time, it got progressively worse. I started to struggle to engage in intimacy because it would often end in me crying in pain. My partner was thoughtful and attentive and always stopped if I was not feeling well, but it was difficult to navigate because one position would work well one day and cause me severe discomfort the next. Sometimes the pain occurred during sex in certain positions, and other times I would enjoy intimacy and the pain would not come until afterwards. Then I would be hit by a wave of throbbing agony deep inside me that lasted anywhere from minutes to days. What was once a pleasurable way to bond with the person I loved became traumatizing. I was scared to feel the sharp, deep, jolting pain that surfaced during or after sex. I was frustrated and knew that I would need to figure something out because sex is an important part of my romantic relationship that I was not willing to forgo.

Due to the frequency of pain, I started to track my symptoms again. Looking at my period tracking data from October and November of 2020, when I decided to start tracking symptoms again, the days are lit up with tags for pain, cramps, nausea, left side pain, constipation, painful sex, feeling unmotivated, fatigue, bloating, diarrhea, gas, dizziness, feeling emotional, and heavy bleeding. I knew that this was no way to live, and alongside speaking to other people living with endometriosis through online communities and the interviews I was conducting for this project, I started to realize it was time to find an expert.

In March of 2021, I attended the Endometriosis Foundation of America's Patient Day Conference, which was held virtually, free of charge for all endometriosis patients to join. I knew that Dr. Seckin, the Endometriosis Foundation of America co-founder and author of *The Doctor Will See You Now* had performed hundreds of endometriosis deep excision surgeries. Further, his work had given me more information about endometriosis than my first surgeon ever did. Attending the conference taught me why my first surgery was unsuccessful. At the time of my first surgery, I did not understand that there were different surgeries to treat endo. I had no idea about the limited outcomes of cautery, often referred to as ablation. Reading Dr. Seckin's work and attending the Patient Day Conference taught me that deep excision surgery is the most reputable method for treating endometriosis. Unfortunately, it took me a long time to learn that my first surgeon used cautery, a method of endometriosis treatment with an 80 percent resurgery rate.[193] With a deeper understanding of endometriosis treatments, I collected the post-operative reports from my first laparoscopy and read through them to learn more about what my first surgeon had done. I realized that, like so many generally trained reproductive surgeons, the first doctor burned the tissue inside of me, using a method referred to as ablation, leaving the deeper endometriosis tissue behind and creating scar tissue in the process. When I asked the first surgeon's office for the pathology reports that established my endometriosis diagnosis the nurse on the line said, "There aren't any. The tissue was burned so there was nothing left to test." I

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[193] During a phone call with Dr. Kongoasa, an endometriosis specialist from The Center for Restorative Reproductive Surgery, he shared that cautery, often called ablation, has a resurgery rate of 80 percent, whereas deep excision resurgery rates range from 15-20 percent.

started to realize that scientifically, it had yet to be proven that I in fact had endometriosis. I needed to see a skilled endometriosis specialist.

Laparoscopy #2: Finding Relief from Endometriosis Pain

I eventually went to an endometriosis center to pursue treatment with an endometriosis specialist. When I went to the expert surgeon's appointment, it was unlike any other appointment I had ever had. I was ushered into the surgeon's office. After an initial conversation, we went into an exam room and the surgeon conducted a vaginal ultrasound and pelvic exam. The ultrasound was projected on the ceiling so I could see what the doctor was talking about. During the pelvic exam, they inserted their fingers into my vagina and pressed in different locations to ask me my pain level, through which they could determine where there were likely endometriosis adhesions. During the vaginal ultrasound and exam the surgeon said, "Don't act fine, tell me where it hurts." They knew how well patients were trained to perform wellness and hide their pain. After the exam, we sat in their office for over an hour as they answered each of my questions. Well-prepared, I had approached the appointment with a list of questions and a record of my symptoms to share.

The complete list of symptoms and descriptions I brought to the initial consult reads as follows:

- Left side pain: Often (almost daily), throbbing, sharp, aching, intense, sometimes burning, very occasionally same feeling on right
- Pelvic pressure: Like a balloon filling inside me causing pressure or a sensation of feeling as though my abdominal organs are locked up/constricted
- Deep lower back pain: I literally cry from relief when someone rubs it while I am aching
- Pain with intercourse: Sometimes with deep penetration in various positions, sometimes after we finish like a shockwave of pain rushes through abdomen and I can't move
- Nausea: Often with headache
- Bloating and discomfort: Sometimes after a meal, sometimes randomly, I wear loose pants because of it, I literally look pregnant at times
- Bleeding: Used to be major, now I just bleed super heavy for a couple days

After sitting down and consulting with the surgeon, I was advised that pursuing a deep excision surgery would likely provide me with relief that the initial laparoscopic ablation did not offer me.

I went in for surgery in June 2021, alone, because of hospital policies to limit visitors as the Covid-19 pandemic continued to inundate hospital systems. When I woke up from surgery, one of the surgeons visited me and told me, “We found endometriosis and we removed it. Your appendix was enflamed from endometriosis, so we removed it. The endometriosis diagnosis will be confirmed by pathology, but from my experience, what we found was endo.” The validation that I was not making it up washed over me. I was right, and they were able to give me the care I needed. Soon I would discover that the second surgery, a deep excision of endometriosis, led me to find solace in daily life. My days were no longer spent managing pain.

Reflections on an Endometriosis Success Story: To Fertility and Beyond

Enduring years of undiagnosed endometriosis, and a rocky road to receiving adequate treatment, created a sense of insecurity that I buried deep inside. First, the very notion that it was possible that all the pain I experienced was somehow made up was almost as crippling as the pain itself. *What if I am wrong?* It felt like something terrible was going on inside of me, but there were no visual indications, not tests to perform to verify, until pursuing surgery. The association of pain with menstruation troubled me because I felt concerned that perhaps internalized feelings of self-hate could have manifested the symptoms I was managing. Growing up in a patriarchal home with two older brothers, I wondered if the cultural messaging that I was inadequate because of my anatomy could have been so ingrained in my psyche that my physical body started to believe it. Prior to surgery and receiving a scientifically proven diagnosis, before educating myself, I really did wonder if it was my fault. I felt like I had done something to deserve this. I felt like it was my responsibility to get better.

Finally, the deeply entwined cultural messaging that women are meant to be mothers challenged my perception of self-identity when I realized I was facing a disease that often restricts fertility. For a long time, I convinced myself that I never wanted children, and as I reflect on it now, I believe it was a coping mechanism of self-protection because at the time, I feared whether my fertility would be preserved by the surgery. After my deep excision surgery, I was told that there are no indications that I will have difficulty conceiving. Whether or not I will choose to carry a child is yet to be determined, but for now, having the option on the table is an opportunity I am grateful for, as so many others with endo have that decision taken from them because of their illness.

Pain is not normal. There is no shame in sharing that you are suffering. It has taken me a long time to really believe that. I performed wellness for years. I showed up to classes in this PhD program at CGU and participated as if nothing was wrong when I felt like crying. I attended work calls when the throbbing burning pain in my left ovary was distracting. I am guilty of saying, “fine” when what I meant was, “I wish I could step outside of my body.” I pretended to be okay to cope with a situation I did not understand. Then I continued to perform wellness to save face when I realized that the road to treatment and recovery would take longer than I expected.

Having been through this experience with endometriosis, I am skeptical of the United States medical system and no longer trust everything that doctors tell me. I am now accustomed to taking information from doctors and then going home to pursue my own research on it. The advice I offer because of this experience and the insights that have come from this research is that it is important for people to always seek information on their own and to get a second or third or fourth opinion when something does not feel right. Pain, in any form, is not “normal,” it is a message that something in your body is out of equilibrium. Take pain seriously and do not allow anyone to convince you that the pain you feel is not real or that experiencing pain is normal. The more we speak openly about menstruation and fertility challenges, the more likely we are to spread awareness that diseases like endometriosis, which effects one in ten people with internal reproductive anatomy, require timely diagnosis and treatment. Endometriosis is uncomfortable, so in the process of this research I have stopped worrying about other people's comfort around the topic of menstruation. Rather than normalize pain, we should be normalizing conversations about menstruation and discussing the endometriosis symptoms that cause so many people distress. I will continue reading, writing, and speaking openly about endometriosis because I do not want the stories that the participants shared, or my story, to continue to repeat itself for generations to come. We might be able to put an end to endo symptoms for the 200 million living with it, but it will require making noise about it first.

An Endometriosis Dissertation

Talking in-depth with people about their firsthand accounts of endometriosis was an overwhelming process. Although I am proud to give space to their voices, it takes an emotional toll to recognize how widespread the patterns of dismissal, misdiagnosis, delayed diagnosis, and medical sexism are. Learning from the participants how they have pursued so many doctors and spent so much time educating themselves to get to the point of reaching a diagnosis has been difficult because it seems so obvious that the pattern of endometriosis delayed diagnosis is avoidable and an unacceptable reality. My research emerged from a desire to know more about how my experience compared to that of others with endometriosis to understand the trends of delayed diagnosis and why this continues to happen so frequently. The process has highlighted some glaring patterns as well as anomalies in endometriosis patient experiences, all of which provide us with a better understanding of where things are for people living with the disease so that we can find a way forward, towards a culture in which menstrual-related symptoms are recognized for their potential causes and evaluated medically as such.

Writing this chapter was difficult. Reflecting on the medical experiences I had faced brought many emotions to the forefront. First, I am so grateful to sit here pain-free and write. I feel lucky to have had the privilege to get treatment from one of the leading endometriosis specialists in the world. Although I do continue to experience occasional discomforts, I am no longer debilitated by endo. Conducting this research was empowering, as speaking with other people who shared their stories encouraged me to continue seeking answers and advocating for my health, despite the challenges of doing so while living with chronic pain. Yet, I simultaneously feel guilty, because I recognize that the successful outcome in my story is a rarity. My heart continues to ache for the other people living with undiagnosed or untreated endometriosis who continue to struggle with symptoms daily. Some folks who do get adequate care still struggle because the delayed diagnosis allowed time for the disease to spread and create irreparable damage to their internal organs. I am saddened for everyone who has had to endure the symptoms of endometriosis. I am also sad for the loved ones of folks living with endo who struggle to cope with watching a loved one suffer, or who are challenged by trying to navigate something they cannot understand.

Although my work does bring sadness, frustration, grief, and anger towards the complexity of ways through which cultural factors influence the delayed diagnosis of endometriosis, I remain optimistic. I hope that by centering the voices of people living with endometriosis, I can contribute to spreading awareness about endometriosis and the complexity of living with the disease. Writing this free from pain should set a standard for people living with endometriosis and their medical providers. Better care, quicker diagnoses, and increased use of the best methods for treating endometriosis are necessary. My story provides a case study of the possible outcomes for people with endometriosis. Like so many people with endo, my first endometriosis laparoscopy did not help. However, I was lucky to only require two surgeries to find relief from my endometriosis symptoms. For many people living with endo, their diagnosis is only a step in a process of multiple surgeries. However, my case proves that it does not have to be this way. Rather, there needs to be increased training of deep excision for reproductive surgeons addressing endometriosis cases to avoid the high resurgery rate and to help people with endo find long-term relief sooner. Endometriosis is highly treatable and there needs to be improved awareness of this fact.

Conclusion

Tiny little scars born of battles
Still being fought beneath them.
There is a part of me
That fears these walls
Are as far as my dreams go.
I am so frustrated
By a world that cannot see
That, given the chance,
My worst work
Would top their best.
I fear I will live in a world
That can not accommodate
Anyone who does not,
Cannot,
Will not,
Grind themselves until their
Bones begin to scream
Like a train warning:
Stop!
A crash is fast approaching.
I am exhausted
Because capitalism
Wasn't made for this body.

-I am sick enough; I cannot work myself to death[194]

Throughout this dissertation, I have centered the voices of eighteen people from the United States diagnosed with endometriosis who offered one hour of their time to speak with me over Zoom to share their unique experiences with endo. In the process, I have traced patterns of how the medical encounters between people with endo and their doctors have been shaped by cultural ideology. Although the folks from my sample overwhelmingly sought treatment for pain and unmanageable physical side effects due to their endometriosis, there were some participants who approached diagnosis due to their fertility challenges. In both cases, the diagnosis took

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[194] Maggie Bowyer, *When I Bleed: Poems about Endometriosis*, (Greensboro, North Carolina: Margaret Bowyer, 2021), 77.

years, and the average time to diagnosis across my sample was eleven- and one-half years. The stories shared across my sample indicate that the delayed diagnosis of endometriosis is a result of sexist medical ideologies that mythicize menstrual pain as a normal part of menstrual life. Due to dominant cultural rhetoric, such as that touted through self-help literature, participants in this study shared how they adopted a coping strategy to publicly hide their symptoms, through a phenomenon I coin as performing wellness. I add that the impact of neoliberalism on medicine has reconstituting illness as an individualized experience that the sick person must address, which has led the participants in my sample to self-educate and self-advocate to finally receive an endometriosis diagnosis. In addition to the interviews, sharing reflections through my autoethnographic chapter substantiates the findings from my interviews grounded in my personal experience with endometriosis. Although I hope that this work inspires folks struggling with undiagnosed diseases to learn about their bodies and symptoms and to advocate for themselves in medical encounters, I have also carefully critiqued the tendency for victims of disease to be held responsible for their healing. While currently, folks do need to learn about their ailments and actively push for the care they need when engaging with United States healthcare, my hope is that drawing attention to these patterns will shift the cultural assumptions about the role that ill persons play in their diagnostic and treatment journey.

Limitations

This project is not without limitations. Although I have started the work of uncovering how the delayed diagnosis of endometriosis is not merely a medical conundrum, but a cultural issue of ideological constraints in private spaces, there are more avenues for deepening our understanding of what endometriosis as a case study teaches us about the United States medical establishment. First, I anticipate that some might find concern with my exclusion of doctors' voices throughout this project. When designing my approach to the research question, I selected to center the voices of people who have received a diagnosis of endometriosis exclusively. It is worth noting that some of the participants in my sample work in the medical field, as nurses or public health educators, so there is at least some representation of folks embedded in the medical industry in this work. In future iterations of this project, or to complement the research I have begun, speaking with endometriosis specialists and primary care providers could enhance the full picture of why delayed diagnosis of endometriosis remains such a common trend amongst endometriosis patients. While I did not have the chance to speak with endo specialists or medical workers who do not have an endometriosis diagnosis in this project, one of my major arguments is that people with endometriosis are in fact experts on the disease and have exclusive insider knowledge of endometriosis as persons who have the bodily experience of living with it firsthand. Thus, the exclusion of doctors or endometriosis specialists was an intentional aspect of the study design for this dissertation.

Additional iterations of this project and investigations into the delayed diagnosis of endometriosis might benefit from turning attention to the internet to investigate how online and social media community discourse engages with endometriosis delayed diagnosis. While I did recruit participants through social media engagement, more work can be done to address the endometriosis community through a netnographic methodology. Social media can serve as a vehicle to both reproduce or disrupt the cultural ideology that inhibits the timely diagnosis of endometriosis. Paying attention to the common patterns across endometriosis online communities might deepen our engagement with how the disease is being conceptualized in mainstream public discourse. Considering online spaces as a dataset for expansion of this project, I encourage future researchers to explore Endo Black, Inc.,[195] endoQueer,[196] EndoFound,[197] or MyEndometriosisTeam[198] as unique sites for netnographic investigation. Additionally, there might be interesting avenues for work focused on how algorithms alter what is marketed to people living with endometriosis to see how many people with endo are encouraged to purchase alternative treatments such as TENS units or even self-help texts such as the ones I have critiqued in this study. Additionally, turning to online spaces and virtual communities could complement my argument about how we can turn towards new forms of knowledge production for developing medical knowledge.

Another population that is not represented in the sample are people with endometriosis who do not identify as ciswomen. Since I recruited participants through social media and word of mouth, there is limited gender diversity across my sample. Although transgender men and other people who do not identify as ciswomen can be diagnosed with endometriosis, I did not have the opportunity to speak with any members of the endometriosis population who do not identify as ciswomen. Speaking with people living with endo who identify with different genders could help deepen what we know about gendered conceptions of menstruation and the impact those gendered ideologies have on people with endometriosis. While my sample lacks gender diversity, I have carefully written this dissertation with cognition of the limits inherent in other work about endometriosis that exclusively refer to women. Throughout this project, I have intentionally limited reference to umbrella gendered statements, focusing on inclusive language so that although folks with varying gender identities were not interviewed, hopefully gender-

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[195] Visit Endo Black, Inc. at https://www.endoblack.org.
[196] Visit Endo Queer at https://endoqueer.com.
[197] Visit EndoFound at https://www.endofound.org.
[198] Visit MyEndometriosisTeam at https://www.myendometriosisteam.com.

diverse members of the endometriosis population can still see themselves represented in this work as people living with endometriosis.

Further, my writing reflects the bias I have as an educated, White, straight, cisgender woman, who has had the financial resources to pursue the gold standard of endometriosis care, deep excision surgery. Future work might investigate patterns across specific affinity groups to provide nuanced insights about how experiences differ across identities for people living with endometriosis. For example, critical race scholars might approach the question of endometriosis delayed diagnosis through an investigation of how people's race shapes their unique experiences attending medical appointments in search of endometriosis diagnosis, with attention to the unique constraints of medical racism on Black, Indigenous, and People of Color's experiences. Investigating experiences of people living with endometriosis through standpoint epistemology centered around race, age, or socioeconomic status could provide clearer conclusions about how intersecting identity factors produce additional barriers to access the care that people with endometriosis require.

Finally, this dissertation has exclusively focused on the experiences of people living with endometriosis in the United States. However, the problem of delayed diagnosis of endometriosis spans the globe to varying degrees. The global average time to diagnosis for endometriosis ranges from seven to nine years.[199] Thus, additional investigations of cultural factors that contribute to the delayed diagnosis of endometriosis in differing cultural contexts could complement this investigation. Although this dissertation is not exhaustive, it has both offered conclusions about why there remains a ten-year delayed diagnosis of endometriosis in the United

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[199] Lexi R. Frankel, "A 10-Year Journey to Diagnosis With Endometriosis: An Autobiographical Case Report," *Cureus*. 2022 Jan 17;14(1):e21329. doi: 10.7759/cureus.21329. PMID: 35186587; PMCID: PMC8849430.

States, and it has prompted new inquiries for future iterations of this work or for other researchers to extend this work.

New Directions for Endometriosis Research: Delayed Diagnosis and Treatment

While the driving research question I have started to answer throughout this research is what cultural factors influence the ongoing ten-year delayed diagnosis of endometriosis, the answers I have identified are only a step towards addressing larger problems faced by people with endo. Although diagnosis is a critical starting point for people with endo, diagnosis is a mere recognition of the presence of disease and serves as a catalyst to the process of treatment and healing. Once someone is diagnosed with endometriosis, they at least have a sense of what they are up against and can begin making efforts to treat the disease and heal. However, there are layers of complexity to endometriosis care, treatment, healing, and recovery.

Through a quick online search, there is limited information available to the masses about the nuanced differences across endometriosis treatment options. While most searches of endometriosis symptoms and treatment list pain management, hormone therapy, fertility treatment, hysterectomy, or conservative surgery as common treatments, this list is not often contextualized or elaborated upon thoroughly. Thus, future work can improve the information available to people living with endometriosis and doctors alike about treatment access and efficacy. One important aspect of endometriosis treatment that I must include in this dissertation, although I do not have adequate time to unpack all the nuances of all available endometriosis treatments, is that while the most common surgical treatment of endometriosis is referred to as a laparoscopy, not all laparoscopic procedures are the same. A laparoscopy refers to surgery done through inserting a small camera to view the inside of the abdomen. Then, surgeons often perform either an ablation or deep excision surgery. While I have carefully reiterated throughout this project that deep excision surgery is the gold standard of endometriosis care, I have yet to detail the potential risks of ablation. In short, deep excision refers to removing the entire endometrial lesion through a process of cutting out the tissue, whereas ablation refers to burning the surface level of endometrial lesions. Often explained through the metaphor of an iceberg, ablation scorches the surface of the iceberg without addressing the remaining ice beneath the surface of the water, leaving behind endometrial tissue that will continue to grow. Alternatively, deep excision surgery does extract tissue from deep beneath the surface, removing all the endometrial growth. From my observations of the endometriosis community online, and personal experience being treated with both ablation and deep excision surgeries, I do not recommend ablation to anyone. Ablations lead to more surgeries. Deep excision is the only way to have all the disease removed from the body.

The United States has over 40,000 obstetrician-gynecologists, but most are not trained to do advanced laparoscopic surgery.[200] The most effective form of endometriosis surgery, as I have referred to throughout this dissertation as the "gold standard" of endo care, is deep excision surgery. However, deep excision is not the most widely practiced procedure due to the limited number of endometriosis experts, which is partially due to lack of compensation by insurance companies to surgeons who practice deep excision. According to Dr. Nicholas Fogelson of Northwest Endometriosis & Pelvic Surgery, with properly executed deep excision surgery, the resurgery rate has been estimated at 10-30 percent.[201] However, estimates for resurgery of endometriosis generally are estimated at a much higher rate, indicating that surgeries done using ablation, the most common procedure are aligned with the 40-45 percent resurgery rate by five

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[200] Seckin Endometriosis Center, "Why Is It so Hard to Find an Endometriosis Specialist?" Seckin Endometriosis Center, June 25, 2022. https://drseckin.com/why-is-it-so-hard-to-find-an-endometriosis-specialist/.

[201] Nicholas Fogelson, "Excision vs Ablation for Endometriosis," *Northwest Endometriosis & Pelvic Surgery*. Accessed November 25, 2022. https://www.nwendometriosis.com/excision-vs-ablation.

years following the primary surgery.[202] As previously mentioned, during my conversation with endo specialist Dr. Kongoasa in pursuit of my own deep excision surgery, he suggested that up to 80 percent of patients treated with ablation require follow-up surgeries. The high rates of resurgery are likely attributable to the fact that there are currently only about one-hundred endometriosis specialists skilled in advanced laparoscopic surgery worldwide.[203] Thus, access to adequate surgical treatment for endometriosis is extremely limited for the one in ten people with internal reproductive anatomy living with endometriosis today. An in-depth explanation of why the surgical treatments most widely available and practiced are inadequate to treat endometriosis warrants an entirely separate dissertation.

In addition to developing research on endometriosis surgeries, future cultural analyses of endometriosis could address the economic barriers of endometriosis care costs. Surgical costs for endometriosis laparoscopy range, but overall, the cost of endometriosis care is a barrier for many seeking treatments. The cost of endometriosis surgeries is about $4,923, which is estimated across a sample of people with and without insurance, with those who paid out-of-pocket spending $8,000 or more.[204] Notably, estimates for the average cost of deep excision surgery range from $25,000 to $35,000, not including hospital bills that could reach up to $16,000.[205] Since ablation has been the standard of care for so long, most insurance companies will only help pay for ablation and will not support patients' pursuit of deep excision surgery. Also, because of the limited number of trained deep excision specialists, those patients who do travel to receive

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[202] Sun-Wei Guo, "Recurrence of endometriosis and its control," *Human Reproduction Update*, Volume 15, Issue 4, July-August 2009, Pages 441–461, https://doi.org/10.1093/humupd/dmp007.

[203] Seckin Endometriosis Center, "Why Is It so Hard to Find an Endometriosis Specialist?"

[204] Amber Blackburn, "Out-of-Pocket Costs: Laparoscopic Surgery for Endometriosis," Endometriosis.net, July 9, 2020. https://endometriosis.net/clinical/cost-laparoscopy-surgery.

[205] Shruti Chopra, "How Much Does Laparoscopic Endometriosis Excision Surgery Cost?" All Things Endometriosis & More, September 8, 2021. https://allthingsendometriosis.com/how-much-does-laparoscopic-endometriosis-excision-surgery-cost/.

care often pay entirely out-of-pocket because United States health insurance does not often support patients' care across state lines. People with endometriosis face economic challenges while seeking relief from the often-devastating effects of endometriosis. Future research can extend the work of this dissertation towards an evaluation of the complex economic challenges faced by people with endometriosis to address how many economic barriers to treatment prevent people with endometriosis from healing.

Broader Implications of an Endometriosis Dissertation

The focus on endometriosis as a case study throughout this dissertation can serve as a model for other diseases. Endometriosis is common and the trend of delayed diagnosis is unembellished, but other reproductive diseases such as uterine fibroids and adenomyosis cause similar delays due to their relationship to menstruation and menstrual symptoms. I expect that there are other commonly misdiagnosed diseases or diseases with trends of delayed diagnoses that disproportionately impact certain populations that would benefit from a similar qualitative investigation. I hope that the value I have placed on the firsthand accounts from people with endometriosis's stories in the context of this research speaks to people suffering with disease, medical practitioners, and researchers alike. With my unique position as both a researcher and an individual who has been diagnosed with endometriosis, I have had an opportunity to examine this subject using the resources of my education as a scholar in addition to my firsthand knowledge of the disease to develop the project.

Spending time discussing menstruation and menstrual symptoms explicitly models the type of transition I am calling for in medical education and public discourse. Focusing on the detailed experiences of people living with endometriosis contributes to the reframing of medical knowledge by representing those with endometriosis as experts on the subject. Providing space for people with endometriosis to share their stories and reflect on their experiences emphasizes why open discussions about menstruation, menstrual pain, and reproductive health are important and ongoing. The process of discussing medical topics that have been framed as culturally taboo is a necessary next step in normalizing learning about our bodies so that it becomes more common to recognize when something is not right. Instead of perpetuating trends to look to doctors and medical experts to explain what happens within the bodies of individuals living with a disease through external interpretation, I have tapped the resource of patient firsthand accounts as priority data, emerging from the lived experience of the person who has embodied it. I turn to the insider knowledge of people living with endometriosis because we understand what the disease feels like in a more intimate way than anyone who has merely studied it.

Throughout this dissertation, I have centered endometriosis as a case study for exploring how cultural factors can influence trends in medical treatment. Looking at the delayed diagnosis of endometriosis led to a deeper understanding of how medical practitioners, too, internalize sexist bias and those sexist ideologies seep into their encounters treating patients. Beyond the doctors' common tendency to normalize menstrual pain and dismiss people with endometriosis' concerns about their menstrual-related symptoms, this case study has also contributed to a reconceptualization of what constitutes medical knowledge. By centering the voices of people living with endometriosis, I have disrupted trends in endometriosis medical literature and turned to a new source of medical knowledge production. Rejecting the traditional understandings of medical knowledge production, which position quantitative approaches to experimental, epidemiological, or clinical research as medical research, this project employs an alternative methodology for medical epistemology. In the case of endometriosis, we see that doctors do not even take patient reports into account as valid contributions towards assessing the underlying cause of symptoms, which is an epistemic injustice. I take this a step further by positioning people with endo as reliable informants not just of their symptoms, but of what it means to live with endometriosis more broadly. While historically, medical researchers have not explicitly centered the voices of people with endometriosis as valid medical data, this project is an attempt towards epistemic justice, in which to stories of patients about their experiences with disease are considered adequate for developing medical epistemology and the development of new conclusions about endometriosis delayed diagnosis. The implications of this research extend to other arenas of medicine, in which patients face challenges working with their doctors to identify diagnoses or treatments.

As the emergent field of medical humanities continues to develop, I hope my work provides avenues for researchers to deepen their engagement with medical humanities topics and shift the ways in which we envision medical epistemology. The medical humanities have historically been categorized by the creation of artwork engaging medical topics, the development of medical education through arts and humanities approaches such as art therapy, and the application of a humanities approach to study medicine.[206] My work engages the application of a cultural studies approach to study endometriosis, and I hope it will serve as a model for people interested in transdisciplinary engagements with the intersections of the lived experience of diseases and culture. Additionally, the central lens of gender has situated this project in conversation with gender studies analyses of how biological bodily experience and the gendered identity of individuals are at odds with each other within a hegemonic culture that subscribes to a gender binary. Ultimately, this work provides an example of how medical knowledge construction can be reimagined, and as argued throughout, I reject the epistemic

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[206] Bleakley, *Medical Humanities and Medical Education*, 40.

injustice historically faced by people living with endometriosis by positioning them as the experts of their illness.

Grounded in a transdisciplinary approach embedded within cultural studies, this project sheds light on the importance of humanities scholarship. Although endometriosis research exists, there remain gaps in clearly understanding the delayed diagnosis and common use of ineffective treatments for endometriosis. By shifting the analytical lens to focus on how patients describe their experiences with endo, we gain rich data filled with implications about the pitfalls of a strictly biomedical approach to health in the United States. The biopolitics of endometriosis represent broader ideological constraints to those living with the disease in search of diagnosis. Centering patient accounts as reliable medical data, the humanities approach used throughout this dissertation illuminates how investigating issues with an emphasis on the human component allow for more progressive lines of inquiry that hierarchize human experience over profits. This dissertation serves as a case study for humanities scholars who wish to engage work on topics typically examined within medical research. This work underscores the value of using methods grounded in the humanities to ask questions typically reserved for hard science disciplines and offers one example of how cultural studies support the development of answers to contemporary real-world problems.

Finally, I hope that the implications of this dissertation encourage others to engage with how medical care is practiced in the United States through additional research or policy changes. The ways in which patients are treated by medical practitioners demonstrates a lot about the medical norms within the cultural location of the encounter. When doctors reject the experiences of patients and dismiss their symptoms as medically insignificant and the patient continues to struggle to show up for their daily obligations, there is a problem. Endometriosis provides one example of how cultural messaging can disrupt adequate medical care, and I hope other researchers will apply similar approaches to learning more about other diseases.

Cultural Factors Delaying the Diagnosis of Endometriosis

Although there may be other reasons for the delayed diagnosis of endometriosis, this dissertation has begun to uncover some of the cultural factors at play that influence the decade long search for diagnosis experienced by so many people living with endometriosis. In chapter one, I argued that that the prevailing gendered myths that menstrual pain is normal, that menstrual pain is "all in your head," and that endometriosis should be treated based on intent to conceive, all contribute to the ten-year delay in diagnosis of endometriosis. In the second chapter, I argued that the cultural expectations reified and perpetuated through endometriosis self-help literature contribute to the rhetoric that creates an expectation that people are responsible in their own healing. Then, I discussed how cultural messaging insinuates that someone who does not appear visibly ill should perform wellness by behaving as though they are not ill for the comfort of others. In the third chapter, I argued that self-education and self-advocacy are an important aspect of patient participation in the search for endometriosis diagnosis, which challenge the underlying sexist medical ideologies that people who menstruate should remain silent about their menstrual health. Finally, my project is a manifestation of epistemic justice because I have centered the firsthand accounts of those living with endometriosis as medical experts on their illness. I have argued throughout that the accounts from people with endometriosis centered in this dissertation provide valuable contributions to medical knowledge and the interviews point to some of the factors influencing the delayed diagnosis of endo.

During the process of this research, I learned that people with endometriosis have strength and tenacity represented through their ability to navigate a debilitating illness. Although the people with endo I interviewed have faced pain so severe that they have skipped work, collapsed on hospital floors, or missed out on social activities, they never accepted their doctors' dismissal that the pain was "all in their head." The sample of participants who I interviewed show that the experience of living with endometriosis cannot be ignored and the patterns in their stories highlight the importance of this research. Their stories emphasize that the delayed diagnosis of endometriosis is detrimental to the lives of those living for years with undiagnosed endometriosis. Whether the undiagnosed person with endo is dealing with pain or fertility challenges, the longer it takes to get diagnosed, the more the disease can spread and the worse the lasting damage of endometrial adhesions can develop. My work addresses a cultural problem, of which one in ten people with internal reproductive anatomy are living with this disease, often for years without diagnosis, that needs further attention. The diagnosis of endometriosis is standardized, so we must prioritize improving the time to diagnosis to improve people with endo's quality of life sooner.

Speaking to people living with endometriosis was both validating and heart wrenching. While I have received expert care that has eliminated most of my endometriosis symptoms, many of the people I spoke with have had much more complicated journeys. Although there are some success stories, such as Mia, who lived with silent endometriosis and fertility challenges, who recently reported that she is now a proud mother after a successful embryo transfer, others from my sample have had to accept the lasting damages of endometriosis and the permanent impact it has had on their fertility after undergoing hysterectomies in an effort to combat their symptoms. It is about two-years after my second surgery and I feel that deep excision has given me relief from what once debilitated me. Meanwhile, others from my study have had multiple surgeries and continue to seek treatment to get their symptoms under control.

In this dissertation, I have begun untangling some of the complex systemic and cultural forces that have contributed to the delayed diagnosis of people living with endometriosis to both indicate reasons for this phenomenon and to identify opportunities for improving the time to diagnosis. Reimagining medical epistemology by shifting towards placing value on patient accounts as significant in medical knowledge production might uncover trends that can lead us to quicker endometriosis diagnosis. In this dissertation, I attempted to demystify some of the cultural constructions of endometriosis that are grounded in biased imaginations of ideal womanhood. I have explored how gender has shaped the medical experiences of many people living with endo to address the discrepancy of allowing cultural stereotypes to seep into medical encounters. I hope that medical practitioners will take the accounts of people living with endometriosis recorded throughout this project seriously and start to educate themselves more about endometriosis because of its far-reaching impact. Finally, I hope that my efforts in writing this dissertation can somehow serve each person with endometriosis who engages it- whether they be the participants I interviewed or people pursuing a diagnosis for their unexplained symptoms, I hope that the words I have carefully typed validate your experience, give you hope, and somehow assist you in your quest for diagnosis and treatment to relieve you from the ravages of endometriosis. You deserve to heal.

Epilogue

Here, I turn the remaining pages over to the people with endometriosis I interviewed and highlight some final responses regarding what they wish people knew about endometriosis. In the process of selecting quotations to feature throughout this dissertation, I carefully included quotes from participants that best represented the major themes that emerged from the data. However, the process of writing the dissertation pressed me to contextualize the words that the participants shared with me. Although I centered the voices of the people with endo I interviewed throughout this project, their words have been filtered through the constraints of the dissertation genre, in which I interpret each quote through my own analytical reading of their significance. In this final section, I turn the pages over to participants to offer an additional space for each person interviewed in my study to genuinely speak for themselves. As the crux of my argument hinges on the idea that these participants' words hold value in producing medical knowledge and are enough on their own, this section highlights their voices without further rhetorical influence. I have organized the quotes by alphabetical order of the participants' pseudonym to avoid any further contextualization of their contributions. This afterword provides a final attempt to truly encourage my participants to speak their truth, in their own right.

> Alyssa, 30, CA: I definitely say I have a hate-hate relationship with endo. But I also have this little part of me where it taught me a lot about myself. It taught me how to pay attention to your body, to take time for you, you know? To make sure that you're- if you know there's something wrong with you, then there's something wrong with you. Don't let doctors tell you. Don't let family members tell you. Don't look at- why am I the outlier? No, you need to get your shit together and see what's going on. And that was like that, that came from endo. If I didn't have this, if I didn't deal with this for so long, I don't think I would have been able to say that out loud to be like, 'Oh, well, you know, trust your doctors.' I think that I would have had that mentality. I still do. I still do have the 'trust your doctors,' but you need to trust the right doctors. That's different now. It's, 'Trust the right doctors.' And endo let me know that. Endo had that key distinction in mind now. You need to take time for you, if you know that something's wrong, who cares if you're the black sheep, the outlier, whatever you need to figure it out because your body is letting you know, you just need to pay attention. Then, if you're, you're

encountering doctors who are calling you like, “Oh, it's not, you're talking crazy, it's not real.” Move on to the next one, keep going, you know, stick with it. Find that right doctor. You know? Let them, you know, find the one who will listen to you, who will give you a peace of mind to be like, ‘You're right.’ Validation, you know? I mean, even though you don't really need validation, you know, there's something wrong with you, but just to have that diagnosis, right, just to be like, ‘Okay, I knew it. I didn’t know what it was, but I knew it.’

Aubrey, 27, OK: Ablation doesn't fix it. That is number one. Like, I wish I had known at twenty-years-old. But I thought that because I got pregnant nine weeks after my first ablation that it was fixed that it was magical, that it was all gone. Because literally, I got pregnant with my daughter the first time I had sex after ablation. So, I wish that like, that's the number one. Like, ablation is not a good standard of care, and you should not, like you should have more information than that. And if that's the choice that you choose to make still, then that's your autonomy and your ability to make that decision within your own body. But I feel like you should be given all of the options from the word go. So, but unfortunately, with the medical model that we have, that won’t happen, because money means more.

Brooke, 27, MA: Um, I wish they could understand how just, how painful it is and that it's not just a one system disease. It's borderline a disability. And it effects so many different systems in your body. And I wish that was more widely known. There's a really nice infographic that I came upon. I don't know if you know the artist Halsey? She has endo and she shared this to her story maybe a few years ago. And it really just kind of like struck a chord with me, maybe it was 2019/2020. And it was a photo of a woman's abdomen. And it just looked like, she you know, she was stabbed and all cut up and bruised. And that's what it feels like. You can't see it on the inside. But on the outside, if you were to, you know, visualize it. That's what it looks like.

So, I really wish people understood the toll that it has on your mentality, on your abilities, I really do believe that it's considered a disability at this point. Again, it just has, it has so many side effects, like, you know, it can be very much one of the leading causes of infertility. It's a stressor on like, personal relationships with your partner, because they, they try to understand what you're going through. And sometimes they just can't always understand, you know? The pain. It effects my, my, my mental status, like I don't know if it's me, or, or what, but I feel like sometimes I just, I can't remember things like I used to, or I have this weird brain fog. And I'll just kind of sway. It's very strange. Just so, I just kind of wanted to touch upon those things. And it's stressful in terms of like thinking about your future and family planning. If that's something that you know, a person with endo wants to do, you really have to, like, my doctor rated me on a scale from zero to four of infertility. And he put me at a two. And this is when I was twenty-five. And I'm twenty-seven. So, it's just like it's very, very stressful in terms of family planning and looking at your future as well. It's, it's very unpredictable, and you don't know necessarily where this road is going to lead you. So, it's tough.

Charlie, 28, VT: I wish they knew they had options. Oh, for patients- I wish you know, straight off the bat. Pelvic pain, period pain that is debilitating, monthly pain, pain with sex- not normal. Not normal. You don't need to take ibuprofen and deal with it. Just ask questions, talk to women in your life. Talk to men in your life. I don't care. But, and just, any doctor too like, if you have pelvic pain, just talk about endometriosis. You know, it's like. And if you don't know, I also just want doctors to know if they don't know, it's okay to say you don't know. But to say ‘I'm going to find someone who might know I'm going to talk to colleagues or whatever. I'll refer you elsewhere.’ I don't care. But it's really, I just think it's, it's better to do that than to pretend that you're managing something well, and to lead someone suffering for years and years and years.

Yeah, I mean, I think I mentioned like the importance of mental health, physical health, spiritual health, like all of that. I don't think you can survive this without focusing on all of that, and it's uncomfortable at times. But I think it's definitely worth it. And I know that that's not always incorporated in education or in like, culturally, it's not always, you know, something people have access to, or, you know, resources for that matter, but in some way that, needs to all be incorporated. I also like, people talking about work, too. That's been a really difficult journey, because I think, especially people in our generation, like it's like work, work, work, work, work, work, and that's kind of all that matters, like education/work. And with endo that can be really tricky to figure out. So, I think like, one of the decisions I made was to leave a job that I like adored and was really good at and was well known for and like had a lot of certifications in because of the stress to like better manage my condition. And then just advocating for time off when I need it. Noticing when I'm kind of getting to a place that's like, not so good. And like what kind of healthy coping mechanisms like getting a counselor, even when you're in a good place, like someone checking in with you on that kind of stuff and asking you those questions, big time. Meeting with a naturopath as well as a regular primary care doctor and a specialist and an OBGYN. Because there's always benefits in combining therapies, massage, yoga, diet, like, I just want to talk about everything. I just feel like I've learned so much in such a short period of time. And you're one of the first people I've talked to. So, it's just like, oh, my God, there's so much!

Connie, 26, WA: To believe them [people with endometriosis]. Believe their symptoms. Believe their pain. Like, they're not telling you this just to play with you. Like, believe their body. Like, if they're telling you, ‘Hey, my body hurts, this and this and this.’ Don't be like, ‘Oh, well. It’s like, everybody has that thing.’ Like, no, like, don't downplay my symptoms, just like you wouldn't downplay someone with cancer or with anybody else. Just because you can't physically see it right now, like, out of my body— it's internally, doesn't mean I don't have it, please.

Grace, 30, IL: Everything! How intense it is. How serious it can get. That it can be on every organ, that it’s a full body disease. I feel like I'm shouting from the rooftops about this. And I just don't feel like anyone cares because they don't experience it. And so, I really would like it to be something that is talked about, understood, looked at, like, less people have diabetes, right? Or the same amount, something like that. And everyone knows what diabetes is. Because it affects men and women. So, I want people to know everything. Like what we experienced, I want them to understand how intense it is, I want them to be able to recognize symptoms in someone else and say, ‘Hey, maybe you have that, maybe you should get that checked out.’ But on the other end of it, I want doctors to be able to say, ‘I suspect Endo, and this is what I can do to help you.’ Instead of ‘Here's some birth control.’ You know?... and then there's the correlations, like maybe you shouldn't eat that. Maybe you should stop eating those things because it's probably attributing to your pain. Well, but that's another thing I wish people understood about endo is that your diet really matters forever. And, you know, that, like, there are ways that you can help yourself, even if it's just one percent.

Jade, 42, CA: Just how bad it really does hurt. Just how much it takes. When you're having, when you're having a flare, when you're chronically tired, just how much it takes to actually get out of bed and leave your house. You know? That, like, I feel like everybody that gets up, gets dressed, goes and gets in their car in the morning- when they have this- especially when they're cycling. You get in your car, you get a medal! You make it to work, you make it through the day, you get a, you get a medal. I'm sorry. Like I, I wish people really genuinely understood that it's, it's a chronic illness. It's constant pain, it's constant fatigue. There's no break. There's just really, there's no break.

Kendall, 30, MA: I wish they knew how just like how painful it is and how like, it can like really be debilitating. You know? I think that some people are like, ‘Oh, you're like you're using your period cramps like to get out of work,’ or something like that. But like, it's like, when people tell you that, like they're curled up in a ball or with cramps or they're crying because like, it's, it's real. Like, it's I just wish that they they knew how serious, and that it can, it doesn't just effect you it can effect all different parts of your body.

Kylie, 41, NC: So, it's so the way that it's framed is that it makes it could make you infertile? Or you should have a baby to like. Yeah. I did. One of my friends was told, like, you should have a baby, it'll help like, get better. And it didn't, HA HA! So, then, but she, she loves her kid. But um, she had a baby as a single mom. So, she didn't take it lightly. But, but it was one of those things where it's like, I wish people knew that it is severely debilitating, that it should not be centered around like, you might, it might make you infertile. And or the way to cure it is to have a baby. Like that's the wrong, all sorts of wrong messaging around that, because it's basically just telling women that their body is a vessel for children. That's like, I wish people knew that it's real. It affects women every month. It's, it is truly debilitating. And just because you're not experiencing it doesn't mean it doesn't happen. And it's not. And it's frustrating, because even women, women who have light periods don't even believe other women. And so, it's just really, yeah, it's really frustrating. Like, just want people to believe women and to not see us as like, as like, either it could hinder fertility or having a baby makes it better, like that. I just hate that. Like, I hate that that's what people are told.

Lilly, 33, TX: Find a doctor that you that you mesh well with. It's okay to shop around. In fact, a lot of times we feel that like, ‘Oh, I've gone to this one person, I have to keep going to this person,’ that you don't. You have to put your needs first, and the needs of your body first. Whatever way that looks like for you.

Mia, 38, IL: I wish that more people had heard of it, I wish that it was something that like, you could tell somebody that you had it and they would like, say, ‘Oh, okay, so you qualify for an additional three weeks a year, from family medical leave.’ You know what I mean? I wish that like there was more awareness about it. And that people knew that it existed. I don't care if you know, random people on the street know how it affects every single woman because it is such a diverse disease, it's not important to me that they know, you know what, like, pain with sex or like whatever, clots or you know, anything like that. I don't care about a broad awareness about the symptoms. I just wish that there was greater awareness, that there would be sensitivity about people who are suffering, and so that we didn't have to be so silent about it… Pain is not normal. So, if you're having any kind of pain, talk explicitly about it with your doctor…In terms of like, what I would tell the world about the link between endometriosis and fertility, I would say if you're having pain, or if you're not having pain, if you're having any kind of irregular cycle, you need to be really proactive about it. And you need to be your own advocate and not rely on the doctors to start conversations with you because they don't always do that. And, you know, when it comes to fertility, the earlier you find out that there's an issue, the sooner you can start treatment and potentially reverse an otherwise incurable problem. So, I would just say, talk to your doctor. And if your doctor is not listening, talk to a different doctor.

Peyton, 23, WA: I don't want to say how painful it is because I feel like that's been coming to light more. So that's great. But honestly, I think we need to broaden our understanding of it, and how it impacts people who have it, and learn how to communicate with those who do instead of it just being like, ‘Oh, like, have some pills if you want.’ Like, honestly, having the compassion for people who have endometriosis. It's not fair, that we have to function in this society with an invisible disability, like and to not have it categorized as a disability. If we had more information about it, how it impacts people's lives and everything. I've literally left three of the five jobs I've had because of endometriosis. This is not just a period, it is something that impacts every single aspect of our lives. It's not just painful. It's not just a period. It's not just something that happens once a month. It is constant, it is fluid, and it never goes away.

Raya, 29, CA: I wish that people knew, one, that it exists. And then also that it, while it does affect periods and everything, that it is a full body disease. That it does affect so many organs. You know? Like there's people with it in their brain, which is literally insane to me. So, I think, you know, I think people knowing that it's like a full body disease would make it feel less taboo. Because it's not just talking about like, ‘Oh, my period hurts.’ Like, it's, you know, it's everything can be involved, other than your spleen, as I've learned. But I, you know, I wished that people knew that pain isn't normal, because I feel like there's so many people that think pain is normal, especially women. I think that we're just told like, our pain is normal. I just wish everyone knew pain is not normal straightaway.

Right now, it means to me almost, it's almost a like, it captures women's you know, tireless struggle, almost, you know? Even, even women who don't have endometriosis. I feel like endometriosis is almost like, a symbol of how wronged we are basically because, you know, it's this thing one in ten women have it, which is a lot of women. And you know? We're not heard, we're not seen, we have to do our own research. We have to struggle we have to seek out the right people were wronged by a lot of doctors who don't have the guts to admit that they don't know what they're doing. And so, they do unnecessary hysterectomies and they do all of these things that just make women's lives harder. And so, I feel like it's really just a symbol of how hard it is for us in the medical community.

Sophia, 37, CA: I wish it was seen as a condition as complex and as dynamic as something like cancer so that there could be multidisciplinary practices and things for it. So, maybe not just the general public. You know? If I could have, I wish, I wish they would just know what it is and care. But I guess I just wish that there was more knowledge, at least within the medical community, on the dynamic nature of it and the need for multidisciplinary care. Because, I think if they had more like oncology centers with a, you know, a doctor, a gyno, a physical therapist, a GI doctor, and they saw people in a more comprehensive manner. I wish- I honestly, if I could only do one thing in increasing knowledge and awareness, I would increase it, at least in the medical community, because they're our biggest advocates in educating, right? If they're telling us, ‘It's normal,’ you know? So, maybe just within the community, if they knew truly how dynamic it was, and saw it like a cancer, that spreads, it comes back, it shows up anywhere, that that would actually be kind of cool. If it just got the respect it deserves, you know? It's like, on there and the like, the levels there’s like, cancer, there's AIDS like, you know? If it could just reach that level of like, ‘Damn, people realize it and respect it for what it is.’

Stacy, 45, CA: I wish they just knew about it. Like, what is it? How likely are- what are the, what are the data? What are the stats on it? Like? Where does it come from? Is there any preventative measures that you could take so that you could probably— is there anything that can prevent this? Is it something that's just going to happen no matter what?

Tanya, 37, MS: That it is real, that it exists, that if you're having painful, debilitating periods, it's not normal. You know, I wish I had known just about endo in general. That's not something that I learned in school. It's I mean, even in college, it's not anything that I had ever heard of. So, I just wish it was more talked about. It becomes a household name because so many young girls need to know that when they start experiencing this kind of thing. It's not normal No matter how many people say, ‘Oh, it's normal,’ it's not.

Valerie, 31, CA: That it [endometriosis] is a whole-body disease, that it's not just in your reproductive system. So, when we go get checked, don't just check our reproductive system. Stop doing that stuff. Stop it! Like, you know? Like, they put internal/external X-ray, you know all about the pelvic, but man, hey, it's a whole body. So, test the entire body. And you will see that there's a lot of disturbances.

Zoe, 34, PA: Yeah. I guess like, just generally. I wish that people understood it, first of all, or like, had heard of it. And then secondly, I wish that they understood it is more of a systemic issue. And I think that's the, the crux of it is that the people who have heard of it, which is a smaller subsection are like, ‘Wow, your periods must suck,’ and like they do. But my cramps are the least of it. And so, I, I wish that they, I wish that there was a better understanding of what that was like, as a systemic thing and not like local thing.

Appendix A: Pre-Interview Survey Questions

What is your name?
What is your age?
I identify my sex as...
I identify my gender as...
My sexual orientation is...
What are your pronouns?
Where do you live (city, state, country)?

(Check boxes) Ethnicity:
White, African-American, Latino or Hispanic, Asian, Native American, Native Hawaiian or Pacific Islander, Unknown, Prefer not to say, other

Please note any additional information that you wish to share about your demographic background that you feel was not addressed above...

How old were you when you first started experiencing endometriosis related symptoms?

(Check boxes) Please identify which of the following symptoms you have experienced related to endometriosis:
Abnormal periods, periods with heavy bleeding (menorrhagia), prolonged periods (longer than seven days), painful menstrual cramps (dysmenorrhea), lower abdominal pain, pelvic pain, lower back pain, painful sex (dyspareunia), diarrhea, constipation, painful bowel movements, painful urination, frequent urge to urinate, nausea, vomiting, bloating (sometimes referred to as Endo belly), gassiness, nerve pain in legs, infertility, fatigue, personality changes, shoulder pain, other

Have you been diagnosed with endometriosis? Feel free to share anything you want about your Endo journey...

How old were you when you were first diagnosed with endometriosis?

If yes to previous question, when were you diagnosed with endometriosis? How did your doctor diagnose you (i.e. laparoscopic procedure)?

Have you been misdiagnosed for your endometriosis? Please explain…

What treatments have you tried for endometriosis/endometriosis related symptoms? Was the treatment helpful?

Are you part of any endometriosis support groups (in-person or online)? Which ones? In what ways do you find them useful (if at all)?

Do you believe some aspect of your identity may have impacted how long it has taken to reach a diagnosis? Please explain. (For example: age, gender, race, healthcare coverage, etc.)

(Check boxes) What term do you prefer to use to refer to a person who has endometriosis?

Endometriosis warrior, endometriosis patient, other…

Please note any additional information that you wish to share about your experience with endometriosis here that you feel was not addressed above...

How did you learn about this research project? Why did you decide to participate?

Appendix B: Interview Questions

Are you comfortable talking about menstruation? Have you always been comfortable talking about menstruation? With whom/in what context?

How did you learn about menstruation? Do you remember the first time you became aware that this was something you would experience?

What do you remember about your first period? What is your first memory of having a period?

What connections, if any, do you see between your menstruation education and your experience with endometriosis?

What were your periods like growing up? Do you have any period stories from your own experience that pop into your mind as being particularly unique? Was there something about your periods that was typical for you but uncommon to those around you with their period, such as your friends?

What have your relationships been like with medical professionals?

When did you first think that something was wrong or that you required medical attention for reproductive health issues?

When was the first time you heard the term endometriosis?

Can you remember the first time you told someone about your symptoms related to endometriosis? Who was it? What did they say?

Have you ever been misdiagnosed before learning you had endometriosis? Please explain.

If at all, how long would you say it took you to be diagnosed with endometriosis? If not diagnosed, how long have you been seeking diagnosis? Why do you think it took this long?

In your own words, please describe what living with endometriosis/undiagnosed endometriosis is like.

When you think about your experience with endometriosis symptoms, how do you feel? What does endometriosis mean to you?

Tell me about your recent experiences related to endometriosis. Have you been feeling good, bad, or somewhere in between? Have you had changes to your treatment plan? Has the COVID-19 pandemic impacted your endometriosis care/treatment at all?

What do you wish people knew about endometriosis?

Is there anything else we haven't covered that you were hoping to talk about in this interview?

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