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Wandering Wombs and Wandering Truths: How Physician Dismissal Impacts the Self-Trust of Patients with Endometriosis

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Wandering Wombs and Wandering Truths: How Physician Dismissal Impacts the Self-Trust of
Patients with Endometriosis

Senior Project Submitted to
The Division of Science, Mathematics, and Computing
of Bard College

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Annandale-on-Hudson, New York

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Abstract

“Oh don’t worry these are normal cramps” “Have you been treated for anxiety?” “It’s just everyday aches, there’s no issue” These dismissive statements are too often said to patients with endometriosis, an often debilitating and painful disorder when attempting to diagnose their condition. Whereas the limited existing research on physician dismissal focuses mainly on the medical system, this study aimed to understand the experience of dismissal from the patient’s point of view. Namely, how does dismissal impact the way patients trust their physicians, but more importantly: themselves. The study employed a mixed-methodology approach utilizing the Trust in Physician Scale (Anderson & Dedrick, 1990), the Rosenberg Self-Esteem Scale (Rosenberg, 1965), and an original Self-Trust for the quantitative portion (N=10) and an interview protocol for the qualitative measure (N=1) to explore the emotional experience of dismissal. I hypothesized that patients with endometriosis who had higher trust in the physicians, thus accepting physician dismissal, were likely to have lower levels of self-trust. Pearson correlation coefficient analyses found positive correlations between a patient's trust in a physician and symptoms, patient's trust in physician and self-esteem, and patients' trust in symptoms and self-esteem. A multiple regressions analysis found a significant positive relationship between trust in self and physicians, trust in physicians, and self-esteem; however not in the direction predicted by the hypothesis. This data was further contradicted by the analysis of qualitative data that explored the impact of blaming the patient and the ramifications of damaged trust which was in agreement with my hypothesis such that higher trust in doctors in the context of dismissal led to lower self-trust and self-worth. These conflicting results draw

importance to the issue of dismissal and prompt further research to explore the complexities of the relationship between self, doctor, and endometriosis.

Keywords: Endometriosis, medical gaslighting, dismissal, self-trust, self-evaluation, self-esteem, trust

Introduction

Within the past few years, headlines from major media outlets have highlighted stories of female patients rendered invisible in doctor-patient interactions. From women enduring ten years of being told their pain all in their head to finally receiving a diagnosis of lupus (Dusenberry, 2018) to women with debilitating pain told to “live with it” and that “the pain is normal” to later receive a diagnosis of endometriosis an often debilitating and progressive disease that severely impacts day to day functioning (Marsh, 2021) and to more extreme life-threatening cases of women told to wait it out the pain to eventually die from a stroke because healthcare service workers did not listen (“Naomi Musenga Death”, 2018). Upon these shocking headlines, many shake their heads in awe, wondering how this occurs daily and how it could continue unbeknownst and unremedied.

Despite these cases only now coming to the light of popular media in recent years, it is not a novel phenomenon. Women and people with uteruses have been reduced to beings of hysteria as early as the 5th Century BC when one of the Hippocratic medical texts claimed that “the womb is the source of all diseases” (Gilman, King, Porter, Rousseau, & Showalter, 1993). Even up to 100 years ago, when it was commonplace to dismiss women’s health¹ issues with the surge of credence given to the concept that women were simply hysterical rather than having a

¹ It is important to note that the term women’s health is used throughout this study as well as referring mainly to female patients with endometriosis. This is primarily due to most of the literature using the term “womens health” historically to describe issues of hysteria and disparities. Having said that, I want to acknowledge that people of any gender or without gender can have endometriosis and that transgender, intersex, and gender non-conforming individuals experience immense and unique challenges within the scope of health and being believed. Moreover, the language of some of the cited material would suggest that only women are able to have endometriosis when this is not the case and to leave this unacknowledged would further dismiss the experiences of individuals who experience endometriosis but are not women. However, for the sake of this project, given that only women participated in the study, I am focusing mostly on the experience of dismissal for women patients with endometriosis. Future research and discourse surrounding endometriosis would benefit from a more inclusive stance and discourse in general may consider moving away from using the broad scope of “womens health” as it can be exclusionary to those who face these challenges and are not women.

physical illness; this isolating and damaging phenomenon of dismissal has haunted women throughout history. Although this recent influx of media coverage has led to much-needed research that seeks to understand the persistence of dismissal and potential remedies to the situation, it still prevails as an all-too-common issue with little intervention.

Most of this literature works to establish the existence of dismissal and understand its occurrence from the doctors' perspective; however, this study offers a new patient-centered approach to understanding dismissal. Specifically, I aim to understand the psychological consequences or adjustments that occur in understanding oneself and symptoms that occur after instances of dismissal from doctors with a particular interest in the functionality of trust between one's physician and oneself. I hypothesize that among patients with endometriosis who felt they had been dismissed, having higher trust in the physicians who dismissed them, thus accepting physician dismissal, would likely relate to lower levels of self-trust in their symptoms, and the inverse for patients who placed lower trust in their physicians. I also examine how invalidation and dismissal from doctors affect their sense of self and how this relates to a broader questioning of the power structures in medicine through qualitative research. The ultimate goal of the study is to share patient perspectives that go unheard at the hands of dismissal and offer new narratives to combat the lingering effects of hysteria. To understand why these individual stories go too often unheard and the ramifications of this, we can first attend to the various misconstrued narratives stemming from hysteria that appear to perpetuate and reinforce a standard for dismissal.

Of Hysteria and Wandering Wombs

When many conjure the image of a hysterical woman, they might picture the classic Freud vision of a frazzled and inconsolable woman lying on a plush couch with a psychologist looking over her with an all-knowing smile. While this visualization is perhaps accurate to the

notion of hysteria within the context of the 20th century, hysteria as a concept has existed for thousands of years and once held an utterly different meaning. Though the narrative of a hysterical woman has morphed throughout the years, and the metaphorical chapters detailing the hysteric woman have been rewritten and revised, this underlying narrative persists in reducing the patient to an unknowledgeable, unbelievable, and unreliable body.

The roots of hysteria lie in anatomy stemming from the Greek word *husterikós*, which translates to "coming from the womb"/"suffering due to the womb." (Gilman, King, Porter, Rousseau, & Showalter, 1939). This understanding of hysteria is partially accredited to Plato's wandering womb theory which asserted that the uterus was a free organ wandering around women's bodies. Consequently, because of its free reign to roam the body, it was obstructing respiration and causing problems throughout the body that resulted in various diseases (McCulloch, 1969). With the important caveat that this only pertains to individuals with a uterus, hysteria was at first restricted to those with female sex organs. This theory was also featured heavily in the 5th-century Hippocratic text, "Diseases of Women" (Gilman, King, Porter, Rousseau, & Showalter, 1993) which marks one of the most notable beginnings of the misunderstanding of the uterus and women's health. In the present day, many might guffaw at the concept of an organ freely wandering around one's body; however, given the influence of Hippocrates, one might immediately think of the Hippocratic Oath; we can consider how the basis of this now considerably outlandish theory may have bore an impact on how medical professionals conceptualize patients throughout the past several centuries.

This anatomically focused stance on hysteria, and by extension, women's medical complaints, persisted until the mid-17th century when Dr. Thomas Sydenham, who claimed that though hysteria creates a physical manifestation of symptoms and imitates other diseases, the

"crucial hysterical symptom was always produced by tensions and stresses within the culture surrounding the patient or victim." (Gilman, King, Porter, Rousseau, & Showalter, 1993). A claim that Sigmund Freud and others would later synthesize to be hysteria equating to a psychosomatic condition in response to trauma and other life stresses. But preceding Freud, French neurologist and noted researcher of hysteria, Jean-Martin Charcot studied hysteria in the context of neurology, bringing new meaning to the theory. As historians note, Charcot believed hysteria was an incurable disease that was only observable under hypnosis. Whereas the Greeks conceived hysteria to be the "verheated, labile, voracious, and raging uterus, was now, in Charcot's world, diagnosed as a sexually diseased and morally debauched female imagination" (Gilman, King, Porter, Rousseau, & Showalter, 1993). The implications of hysteria not manifesting as a biological issue, but rather one of a woman's imagination marks a crucial turning point in the discourse around hysteria as it no longer resided in the uterus but rather in the psyche of women. While Charcot was a neurologist at his basis, this helped usher the concept of hysteria into the world of psychology, where the theory began to morph into a concept that most are familiar with once Freud began to study and develop theories around it.

Instead of conceptualizing hysteria as a neurological issue, Freud claimed it was solely problem of the psyche and that hysteria was a result of trauma, more specifically sexual or childhood trauma, expressing itself into physical symptomatology in the process of converting the psychological into the physical (Dusenberry, 2018). Authors and political activists Ehrenreich and English comment that this was the moment in which medicine's understanding of women's health "shifted from 'physically sick' to 'mentally ill.'" (Ehrenreich, & English, 2011), a sentiment many adopted as accurate and led to what many consider the modern diagnosis of hysteria: conversion disorder or the psychosomatization of illness. We can glean from this

winding and evolving conception of a hysterical woman that the somatization of patients has a deep and long history and is a readily available narrative and, to some extent, accepted just in other terms, in the diagnostic process.

We can consider how exclusionary research practices also contributed to the legitimization of the diagnosis of hysteria until the late 20th century when in 1993 Congress passed the National Institutes of Health Revitalization Act, which was an act meant to promote diversity through requirements to include women and people of color (*Clinical trials have far too little racial and ethnic diversity*, 2018). The vast majority of clinical trials' subject pool relied on one sample: white men. These prolonged exclusionary practices both perpetuated and fed the narrative of the hysteric patient at large, which may have contributed to the ongoing dismissal that is being uncovered today. Although these women's symptoms were not unique, when compared to the clinical research norm which was at the time an entirely different biological standard, they were determined abnormal. This made dismissal seem justifiable when the only reason that they were deemed abnormal was that there was no sample in research that was representative of them. This added credence to the belief that if their testimony did not match the standard at the time, despite that standard not being representative, a readily available diagnosis of hysteria seemed to be the most reasonable option at the time.

Disproportionate Treatment in Medicine at Large

Much of the discourse on patient dismissal thus far has predominantly worked to establish the *existence* of dismissal in doctor-patient interactions, particularly for female patients that are treated disproportionately in medicine as a result of this dismissal. Although the pool of research is limited, it illustrates the detrimental implications of years of narratives of hysteria, sexism, and racism in a medical setting. For example, studies have shown that when reporting

acute abdominal pain, women have to wait 16 minutes longer than men to receive treatment in emergency rooms (Chen et al. 2008), women with emergency chest pain also have to wait 10 minutes longer than men and were significantly less likely to be triaged as an emergent case and as a result, less aggressive treatment than men (Reynolds et al., 2021). One study conducted by Johns Hopkins found that in emergency rooms, women that were having a stroke were 30% more likely than men to be misdiagnosed (Newman-Toker et al., 2014). Another study conducted by Dr. Gabrielle Chiamonte that was researching assumptions made based on gender for heart disease, which leads to misdiagnosis, found that when medical students were given identical descriptions of symptoms that indicate heart disease, along with a description of a stressful life event for that patient, 15% of the students diagnosed heart disease in women as compared to 56% in men. Moreover, 63% of the students recommended the man a referral to a cardiologist; only 30% gave that referral to a woman. Perhaps the most critical piece of this research is that after doctors were informed of the stressful life event for the patient, the diagnosis ascribed to women was purely psychogenic as opposed to a physical disease despite the doctors continuing to ascribe the correct diagnoses unrelated to psychogenic causes to the men (Chiamonte & Friend, 2006). These findings tell us that misdiagnosis is rampant across various disorders and conditions and the notion that the irregularity that women experience is mostly due to psychological causes is still consistent today. Because this discourse surrounding medical discourse is so limited, it has rarely taken an intersectional stance when it is necessary as patients of color systematically receive more dismissal and mistreatment within the medical system. This illumination of disparity also helps provide context to the experience of dismissal within a singular patient's interaction with a doctor.

Dismissal in the Doctor-Patient Encounter

To provide a preliminary framework of understanding dismissal in the doctor-patient interaction, we may compare it to something akin to epistemic gaslighting, which stems from the term epistemic injustice coined by Miranda Fricker, described as “a kind of injustice in which someone is wronged specifically in her capacity as a knower” (Fricker, 2007) later, Cynthia Stark reframed the concept with the addition of gaslighting, that is to manipulate someone into questioning their own sanity (Stark, 2019), to expand the notion of repercussions of epistemic injustice “In the case of epistemic gaslighting, the primary wrong is being degraded as a knower. The wrong consists of an affront to one's epistemic competence or trustworthiness. However, in this view, gaslighting has a number of secondary wrongs. These include destroying the epistemic self-confidence of the knower, among others.” (Stark, 2019). If we apply this framework to a medical situation, the patient becomes the “knower” in question, the doctor who expresses bias through epistemic gaslighting. This would look like the doctor, often unintentionally invalidating the patient's lived and known experience based on held biases. Their gaslighting is informed by the aforementioned narratives which may create bias, meaning their justification for denial of their experience is based upon internalized beliefs or narratives about women (i.e. hysteria, over-exaggeration of pain, conversion disorder). The invalidation and dismissal that occurs in these doctor-patient interactions are not exactly gaslighting, per se, as we can consider it largely unintentional and potentially an outcome of implicit bias, and something that is not *intended* to undermine the patient. However, it is useful when trying to evaluate the impact on patients that this dismissal has.

Nevertheless, the understanding of the nature of these interactions points to the invalidation of experience as a key component of what is considered a dismissive interaction and

what is not. It is one thing for a doctor to comment that they cannot help a patient after exhausting all options they are aware of; it is another for them to comment that they cannot help a patient because there simply is not a problem to be helped either because they consider the condition purely psychosomatic or an over-exaggeration. It should be noted that psychosomatic disorders like conversion disorders do exist and are a valid diagnosis; the issue arises when the impulse from the doctor is to describe a patient's condition as psychosomatic when the underlying cause of a patient's complaint is not psychological.

While these overviews of hysteria and dismissal have been discussed in generalized terms, we can consider the ways in which this history is pertinent to endometriosis specifically and how this impacts the diagnostic process. The consequences of hysteria have been felt in the doctor-patient encounter for decades and have been documented by researchers, doctors, and patients alike. In her book “Doing Harm,” journalist Maya Dusenberry compiled patient testimonials to speak to the prevalence of dismissal in the diagnostic process. She noted how some gynecology texts as recent as the late 20th century warned doctors that women often “exaggerate the severity of their complaints to gratify neurotic desires.” (Dusenberry, 2019) to prepare doctors to stave off the psychogenic woman. Dusenberry also noted how Dr. Mary C. Howell observed that in lectures, lecturers exclusively referred to patients using the male pronoun “he,” with the exception of hypothetical cases with a psychogenic origin in which the pronoun “she” was used. She also noted how medical students were often told that women are “unreliable historians” and were characterized as nagging and hysterical mothers (Dusenberry, 2019; Howell, 1974). Some may argue that these stark misconceptions are a thing of the past, but a study published in 2018 by Young Fisher, and Kirkman used a qualitative approach to understanding gynecologists (GY’s) and general practitioners (GP’s) conceptions of patients with

endometriosis found that some practitioners still held the psychological conditions of the patient as important, if not more, than their physical symptoms “In her case... I think it [her symptoms] stemmed from a bit of, you know, parental, matrimonial disharmony, so there’s a little bit of that, you know, like a psychosomatic expression of, of the wider problem within the family.” (Young, Fisher, & Kirkman, 2018) as well as using “extreme adjectives and hyperbole to describe women’s experiences: ‘driven them over the edge’ (GY1), ‘go out of their mind with pain’ (GY4), and ‘they’re all anxious to get treatment’” (Young, Fisher, & Kirkman, 2018) Young continues to explain how references to hysteria were made both overtly and covertly by nearly all of the GY’s regardless of gender. While these expressions of the hysteria discourse are perhaps more subtle, it displays how even today, deeming a woman psychosomatic is an impulse that is not yet quelled, whether or not the practitioners are aware of it. Though hysteria was only one component of how patients with endometriosis have been historically dismissed, the characterization of the endometriosis patient in the popular press and medical discourse seems to bear a similar weighty influence on this mistreatment.

Endometriosis

Like hysteria, endometriosis’s name also comes from Greek roots with the word “endo” translating to inside, “metra” being the uterus and “osis” translating to disease. (Tsamantioti & Mahdy, 2022). Endometriosis is a chronic inflammatory disease that results from tissue similar to the endometrium, which is the tissue lining the inside of the uterus, existing in spaces outside the uterus and pelvic organs (Parasar, Ozcan, & Terry, 2017). In turn, this tissue results in painful and often debilitating symptoms that can occur both related and unrelated to an individual’s menstrual cycle. Endometriosis is both a chronic and progressive disorder, meaning it is a condition that can last years if not a lifetime and can progress over time which many patients

must endure given the extended length of the diagnostic process. Endometriosis is generally outlined in four different stages: Minimal (I), Mild (II), Moderate (III), and Severe (IV) which is marked by the amount and severity of the endometrial implants and reported symptoms. Though the most prominent symptoms are reported as pelvic pain, dyspareunia, excessive menstrual cramps, infertility, and irregular menstrual cycles, individuals with endometriosis can also experience intense nausea, bleeding between cycles, fatigue, and pain not localized to the uterus.

The discovery of endometriosis seems to have as tumultuous of a journey as those who seek a diagnosis for it. While John Sampson first named it in the early 20th century, it was first identified by Austrian pathologist Carl von Rokitansky in 1860, who provided the first description of endometriosis after finding uterine polyps, that he categorized as cystosarcoma which is known as a painless tumor. (Acién & Velasco, 2013; Christiano, 2019; Nezhat, Nezhat, & Nezhat, 2012). Despite the tissue and lesions being benign and far from painless, leading to some later misunderstanding about the nature of endometriosis, this was the first significant step in identifying a physical cause for the pain patients were experiencing. However, it was not until Sampson published an article in 1927 that the term endometriosis first appeared. Even after this labeling, the understanding of endometriosis and how to treat it remained blurred and many patients with endometriosis question the slow progress made to find more accessible forms of diagnosis (Hudson, 2021). Though endometriosis was formally discovered in the mid 19th century, some scholars speculate that there is substantial evidence to suggest that a majority of medical cases that received a diagnosis of hysteria may have been endometriosis (Nezhat, Nezhat, & Nezhat, 2012) which, if true, could be considered “one of the most colossal mass misdiagnoses in human history, one that over the centuries has subjected women to murder, madhouses, and lives of unremitting physical, social, and psychological pain.” (Nezhat, Nezhat,

& Nezhat, 2012). This is because many of the scholars and researchers who studied hysteria at the time reported strikingly similar symptoms to endometriosis.

Beyond the clear link between hysteria and endometriosis, the choice to focus on endometriosis specifically, as opposed to other conditions in which patients overwhelmingly face dismissal before achieving the correct diagnosis like fibromyalgia (Durif-Bruckert et al., 2015) chronic fatigue syndrome (McManian et al., 2019), and general chronic pain (Iglér et al., 2017), is that endometriosis uniquely relies on the individual as a “knower” to prove the validity of their symptoms as obtaining a diagnosis almost always requires an invasive surgery called a laparoscopy. The surgery requires a small incision in the abdomen to insert a tube with a small camera to obtain imaging of the abdomen and pelvic organs. (Cleveland Clinic, n.d.) Because it is an invasive surgery, many doctors will not suggest the surgery upon first hearing symptoms, leaving women needing to convince their doctors of the validity of their condition based purely on the believability of their phenomenological and felt symptoms. Due to this lack of science to easily diagnose someone with endometriosis, the role of the patient as the “knower” is crucial as the patient is effectively tasked with proving the legitimacy of their pain; a task that is based on cases of systemic dismissal and misconceptions about the condition is often met with undesired apprehension. Despite the individual being the one most knowledgeable about their symptoms, the Endometriosis Association’s research registry has found that 61% of women and girls diagnosed with endometriosis have been told by healthcare providers that there is no problem or anything wrong with them (Latthe et al., 2006). This points to a mass issue of testimonial injustice and women not being taken seriously as “knowers”.

“Career Woman's Disease”, Characterizations, and Stereotypes that Lead to Dismissal

For decades, the narrative of endometriosis evoked one main character, or rather archetype, that disease was considered reserved for: upper middle class, working, white women (Carpan, 2003). A 2003 study by Carolyn Caplan that surveyed the representations of endometriosis in the popular press and medical literature between 1975 to 2001 found that many journals focused more narrowly on symptoms, most revolving around fertility issues and lifestyle changes to accommodate “self-healing”. Although, some feminist magazines gave initial reports on the issues of misdiagnosis in patients with endometriosis (Carpan, 2003). In popular media, coverage of endometriosis was often more interested in the characteristics and lifestyles of those getting endometriosis rather than understanding the condition itself. From these representations, endometriosis became colloquially known as the “career woman’s disease” (Carpan, 2003), which we now know is a falsity. Still, we might consider the ways in which this labeling has contributed to further dismissal of anyone experiencing endometriosis who did not fit this narrow characterization. This characterization followed many findings and claims published in medical journals that focused on the individual who had endometriosis rather than the condition that contributed to the growing misconception that only endometriosis only impacted businesswomen, particularly those who were white.

The label “career woman’s disease” originated out of the belief that women were getting endometriosis as a result of “neglecting” their reproductive system by delaying marriage or pregnancy; in essence, inferring that women themselves were to blame for their pain and fertility problems (Carpan, 2003). Typically, the women diagnosed with endometriosis, and coincidentally often delaying marriage and pregnancy, were career women, which is how this theory of endometriosis earned its title. But that does not mean they were the only patients affected by endometriosis, perhaps only those who were able to access the correct resources to

obtain a diagnosis, an assertion not widely considered by medicine at the time. The catchy label was not only distributed amongst popular media left and right, but even in medical journals and textbooks (Darrow et al., 1994). This characterization was even formulated and published as a theory by gynecologist Joseph Vincent Meigs, who depicted endometriosis as a lifestyle disease that he felt only impacted white, middle-class women and was likely to be rare in nonwhite women. (Meigs, 1938) Based on his personal observations, Meigs theorized endometriosis to be more common in his private patients than in patients in general hospitals without taking the racial and socio-economic implications and disparities preventing access to private health care into account (Bougie et al., 2019). Unfortunately, this theory spread throughout medicinal discourse and into popular media, ultimately cementing the term.

The most salient danger of this characterization lies in how it fueled misconceptions about the nature of endometriosis and misconceptions about *who* can develop endometriosis, namely, how it fostered even more exclusivity for people of color. Women of color already bore the brunt of much of the dismissal perpetuated in the medical setting (Hoffman et al., 2016); therefore, claiming that this was disproportionately a white woman's disease was a damaging characterization that may have contributed to the misdiagnosis of many black women. These implications can be understood in a study conducted by gynecologist Donald L. Chatman in 1976 found that while 1 in 5 black women who received care from him had evidence of endometriosis, of those women, 40% had been wrongly diagnosed with pelvic inflammatory disease (PID), which is a complication caused by STDs (Chatman, 1976). Chatman argued that this was likely the cause of this mass occurrence of misdiagnosis along with the characterization that black women often receive as being “promiscuous.” There is no definitive evidence that the characterization of the typical patient with endometriosis, however, at the time as a white

middle-class woman impacted the rates of misdiagnosis in non-white women, considering many gynecologists in the mid to late 20th century agreed with this specific and exclusive stereotype of who gets endometriosis it does not seem unimaginable.

As research progressed, this characterization seemed to fade; however, we can speculate if the exclusive associations between endometriosis and what an endometriosis patient looks like are still felt today in the diagnostic process. Based on literature reviews and patient reports, scholars stress that implicit bias or stereotyping likely still exists in the medical community, fueled by these antiquated yet resistant conceptions (Bougie et al., 2019). This suggests that whether practitioners are aware of it or not they may be impacted by these narratives and characterizations that have accompanied endometriosis since its discovery.

With this in mind, endometriosis is a condition that, unlike most, seems to have a specific narrative lurking underneath the physical fact of the disorder. Although patients with endometriosis already face immense difficulty in achieving a diagnosis without being dismissed or misdiagnosed, the past racist and classist misconceptions surrounding the condition stress the importance of understanding the diagnosis through an intersectional lens. Namely, understanding the added difficulties that such a stereotype pose to non-white women can make it even more challenging to obtain a diagnosis and feel heard by medical professionals.

Effacing Sense of Self Through Dismissal, Self-Trust, and Testimonial

Much of the existing literature studying trust in doctor-patient relationships emphasizes the trust a patient has in their doctor, but what seems equally relevant but significantly less studied is how instances of epistemic injustice may affect the way a patient evaluates their own symptoms, namely to what extent they trust their symptoms. Much like gaslighting at the root of this dismissal exists a perceived truth that the patient or knower, to use Fricker's term,

experiences are invalid and one could consider that some can interpret this that their life experience, beyond symptoms, is invalid. Whether this invalidation is intentional or not, if the patient accepts the dismissal as true, they are likely left with a feeling of uncertainty over who is supposed to know their body best. In cases of dismissal, they are either prompted to trust the doctor, who by invalidating their symptoms is by extension is invalidating their lived experience; this ushers the patient into a space of ambiguity wherein their sense of trust in their own lived experience is effaced if they agree with it. Moreover, the experience of providing a perfect testimony in order to convince doctors of their pain. In this sense, doctors are made the gatekeepers of care, and the key is the extent to which patients' own lived experiences are believable and valid in the eyes of the doctor. If dismissed without recommendation or commitment to exploring other avenues of treatment, it can be assumed that the patients lived experiences are deemed incorrect thus effacing certainty of truth within the patient's lived experiences.

Though it is understandable that doctors want to make sure that the patient likely has endometriosis, given that the laparoscopy is an invasive surgery, this results in years of debilitating pain and often countless experiences of that pain not being fully acknowledged or accepted by care providers that could possibly be shortened by taking the patient seriously. This makes the patient's testimony of their symptoms one of the most crucial facets of the diagnostic process, but perhaps even more important is the acceptance of the testimony. As explained earlier, it appears that years of accepting hysteria and stereotypes may be internalized and result in disproportionate care. The dependence on acceptance of a patient's testimony is precisely the reason why this project works to understand how this often repeated denial may impact a sense of self-trust. It begs the question, does denial of testimony equate to a denial of the life

experiences of these individuals, and who are the patients that experience confusion and a lack of self-trust in their symptoms as a result?

Though self-trust has not been studied directly in cases of illness, and specifically endometriosis, one qualitative study focused on the general experience and emotions women with endometriosis had after being dismissed by their doctor; from their data, they elucidated an overarching theme of distrust (Johansson et al., 1996) which adds credence to the choice to study trust as it relates to patients experiencing dismissal. The notion of self-trust can be evaluated in a wide variety of contexts; however, for this current study, it seems most important to investigate self-trust as specific to symptoms and, in a broader sense, how may self-trust relate to self-esteem and understanding of symptoms.

Methods

Given this information, I considered the following question: how do instances of dismissal from doctors affect trust within the relationship between doctor and patient when dismissal is present, but more importantly, between patient and self? I hypothesized that a higher sense of trust in one's physician in the context of dismissal is likely to correspond to lower levels of trust in one's own symptoms, equating to a lower sense of self-trust as it relates to endometriosis. I consider trust in physicians as the predictor variable and the dependent variable as self-trust and hypothesized self-esteem to be a mediator with the prediction that someone who sees themselves negatively will likely have lower levels of self-trust. This study utilized a mixed-method methodology employing quantitative research to test the hypothesis through a survey and qualitative research using interviews to get a deeper understanding of the manner of dismissal, and the features of impact it may have had in a more explorative process.

Prescreening

For participants to be considered eligible, there were three criteria: first, they were required to be 18 or older; second, they had to have an official diagnosis or recognition of endometriosis, presumably from a laparoscopy but will accept other forms of formal recognition of the disorder, and finally must have had experienced at least one instance of dismissal from a doctor. To ensure a sample that met these criteria without exposing the aim of the study in recruitment, a pre-screening measure preceded the survey, which asked questions to determine eligibility. If determined eligible, participants continued on to the rest of the survey.

Participants

Participants were recruited via online endometriosis support groups primarily from Facebook and established virtual support groups. While 15 individuals responded to the survey, five participants were excluded due to incomplete data or not meeting the criteria for being included in the survey resulting in a final number of ten total participants (N=10). Participants who completed the quantitative portion received \$2.50 for compensation for the survey, which took approximately 15 minutes in accordance with U.S. minimum wage and \$15.00 was given for participation in the qualitative interview portion. Participants were between the ages of 22 and 53 ($M_{age}=34$, $SD_{age}=11.6$), which, was considerably expected given the ages with the highest reported incidence of endometriosis range between 21 and 29 (Schrager et al., 2013), and although the onset of endometriosis can start at as early as 11 years old, it can take six to 10 years to receive a formal diagnosis (Hadfield et al., 1996, Arruda et al., 2003). 90% of participants were white and 10% reported as other, and 30% identified themselves as Hispanic or Latinx (60% did not, and 10% reported as other).

Materials

The quantitative portion of the study took form through a self-report survey that employed three scales given to the participants framed in the context of dismissal: Trust in Physician Scale, Rosenberg Self-Esteem Scale, and an original Self-Trust scale. All scales were adapted into a 5-point Likert scale ranging from strongly disagree to strongly agree for consistency purposes. To structure the qualitative component, I developed a 27- question interview protocol to get further emotional information about their experience of dismissal.

Trust in Physician Scale

Developed by Anderson and Dedrick in 1990, the Trust in Physician scale (MCronbach Alpha= .87) aimed to measure interpersonal trust between the patient and doctor. The scale features questions that refer to likeability and perception of compassion from the provider and assesses the level of trust a patient has in their provider regarding medical information and decisions (Anderson & Dedrick, 1990). In addition, I use this scale to mark how many participants accepted the dismissal at that moment in time, meaning that higher scores of trust might suggest higher acceptance of dismissal. (See Appendix F.)

Self-Trust Scale

The majority of the current literature on trust examines interpersonal trust levels and measures trust in a way that is not relevant to the current study, because of this I have created an instrument that explicitly measures self-trust levels in patient's symptomatology. It would be ideal to use an established scale that has undergone pilot testing, nevertheless, there is not a relevant instrument that currently exists. The questions pertain to the degree of trust that one has in their symptoms after facing an instance of dismissal, ask about trust of their interpretation of

their symptoms over their doctor's interpretations, confidence in their symptoms being real, and other related questions. (See the Appendix H.)

Rosenberg Self-Esteem Scale

In order to assess self-esteem as a potential mediating variable, I chose the Rosenberg Self-Esteem Scale. The scale was created in 1965 originally to investigate adolescent self-image but has been used as a consistent measure of self-esteem with good test-retest reliability ($r = .85$) (Rosenberg, 1965). The relevance and usefulness in the scale lies in its aid in revealing insight into how self-trust of symptoms relates to self-esteem on a broader range that spans beyond self-perception as related to one's illness. (See Appendix I.)

Knowledge of Endometriosis

Initially, an exploratory variable of knowledge of endometriosis was going to be utilized to understand the relationship between knowledge of the disorder and trust to explore questions surrounding accessibility and if knowledge of the disorder is a potential tool to combat the impact of dismissal. This question was included in the demographics section, however, after data was collected it was realized that the Likert scale questions were written in a confusing order, and disagree and strongly disagree were not an option, this analysis has been excluded as a result.

Interview Protocol

To ensure that interviews would be consistent among participants in a semi-structured format, I created an interview protocol matrix split into four sections that correspond to the following variables: The interview questions are split into four sections that correspond to the four variables I am interested in learning about, namely, self-concept, levels of empowerment, health outcome, and self-trust. The protocol, which can be found in the appendix, poses

questions to prompt participants to give more detail about the dismissal they faced, what emotions they might have felt as a result, the ways they did or did not feel heard by their physicians, and more. The ultimate goal of creating the interview protocol was to obtain answers that would help tell the story of the numeric data collected in the survey, thus the questions were posed to elicit a more detailed and elucidatory description of their experiences with dismissal. (See Appendix J.)

Procedure

Each recruitment post (see Appendix B.) listed in the various online support groups ended with a link to the study on Qualtrics. Participants first answered the pre-screening questions (see Appendix E.) to determine eligibility for the study and if they met the criteria they moved on to a brief demographics section (see Appendix F.) and proceeded to the main part of the study. Before each scale, participants were asked to recall a time in which they were dismissed and answer the survey questions according to how they felt at the time of dismissal, rather than in reflection of how they felt at the time or currently feel. After completing the survey, they provided their compensation information and were offered the ability to opt in to giving an interview, if they decided to opt-in, they provided their contact information and awaited to be contacted.

Participants for the interviews were initially planned to be chosen through random sampling, but due to the low response rate, the three participants who indicated that they were interested in partaking in an interview were selected and contacted. However, only one of the participants responded and was consequently scheduled and interviewed, guided by the interview protocol, which lasted around 30 minutes and was held on Zoom. Following the interview, the participant was fully debriefed on the study and received a link to provide compensation

information. Because the other participants were not debriefed after the survey due to them opting into the interview and could not be debriefed after the interview as communication was lost, participants were sent a debriefing form via email to ensure that they had the information even if not received in real-time. Only the audio file from the interview was retained and was kept safe on a password-protected file on a password-protected computer and was then transcribed for analysis. (For further information on privacy measures see the IRB materials Appendix D.)

Results

Quantitative Analysis

Before considering the quantitative results, it is important to contextualize the findings with the circumstances of the study. Despite the presence of significant results, given that the expected sample size was 60 participants, the final included sample was 10 and with the replication crisis that has swept across multiple scientific fields, particularly psychology, it is irresponsible to not acknowledge the impact that this smaller sample size might have on creating such strongly significant results by chance thus increasing both type I and II error (Faber & Fonseca, 2014; Columb & Atkinson, 2016). With this in mind, when analyzing the results it should be understood that these results may not necessarily be generalizable or necessarily replicable but only the first step in this work.

Before attending to the main analyses, to understand how these variables might compare to a more general sample, I considered the means of each variable, trust in physicians and self, as well as self-esteem. However, because there was not a second group who did not experience dismissal to use as a point of reference, I compared the scores of participants across a test average of the Likert scale of 3 using a one-sample t-test. I expected that there would be a

significant difference between average scores of trust in physicians, self-trust, and self-esteem. First, in comparing trust in physicians to the test value of 3, patients who experienced dismissal did not report significantly different scores of trust in physicians ($M = 3.29$, $SD = .60$) when compared to the scale average $t(9) = 1.525$, $p = .162$. Patients who experienced dismissal also did not report significantly different scores of self-trust ($M = 3.7$, $SD = .69$) when comparing to the scale average $t(9) = 3.18$, $p = .011$. Finally, patients who experienced dismissal did not report significantly different scores of self-esteem ($M = 2.86$, $SD = .69$) when compared to the scale average $t(9) = -0.623$, $p = .549$. (Table 6). These results are not consistent with my hypothesis, meaning that despite there being significant relationships within the sample itself when comparing to the scale midpoint or hypothetical average there is not a significant difference between patients and the average. It is worth noting, though, that the only negative t-value found was in self-esteem suggesting that patients, in this sample at least, have slightly lower self-esteem when compared to the average. It is compelling that in comparing means self-trust is slightly higher than the other variables, suggesting that patients have a higher sense of self-trust than other variables, though not enough to be considered statistically significant.

Then, to understand the functionality of the variable of trust in how it relates to the relationship between doctor and patient and patient in self, I conducted a Pearson r correlation coefficient to test relationships between the three variables. Specifically, to evaluate if patients had high scores of trust in their physician, would they have a lower sense of trust in their symptoms, which I had hypothesized, or lower. A Pearson r correlation between trust in

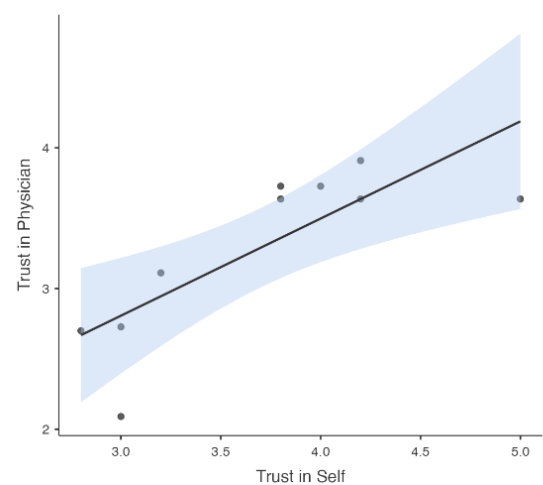


Figure 1. A scatter plot and linear regression of the Trust in Physician Scale (y-axis) and the Trust in Self Scale (x-axis) from 10 participants. (Pearson's $r = .83$, $p = .003$)

physicians and trust in self found that patients who had trust in their physician are also highly likely to have a higher sense of trust in their symptoms $r(9) = .79, p < .05$ (Figure 1). The second correlation found that patients with a high sense of trust in their physician also had a high amount of self-esteem, $r(9) = .76, p < .05$ (Figure 2), though this relationship was not as strong as the first correlation. Finally, a third strong positive correlation was found between patients' trust in symptoms and self-esteem such that patients with a strong sense of trust in their symptoms also have a higher sense of self-esteem in general $r(9) = .81, p < .005$. (Figure 3) (Table 1).

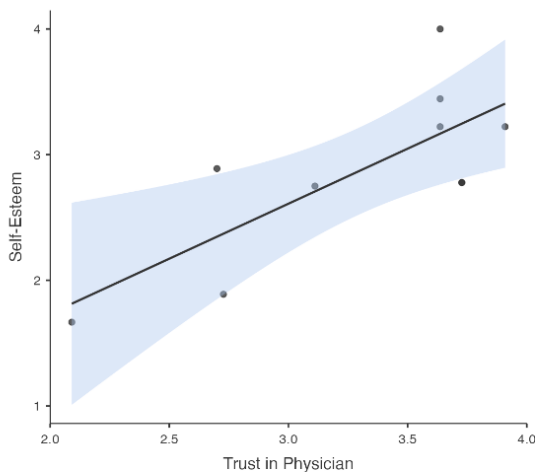


Figure 2. A scatter plot and linear regression of Rosenberg Self-Esteem Scale (y-axis) and the Trust in Physician Scale (x-axis) from 10 participants. (Pearson's $r = .63, p = .048$)

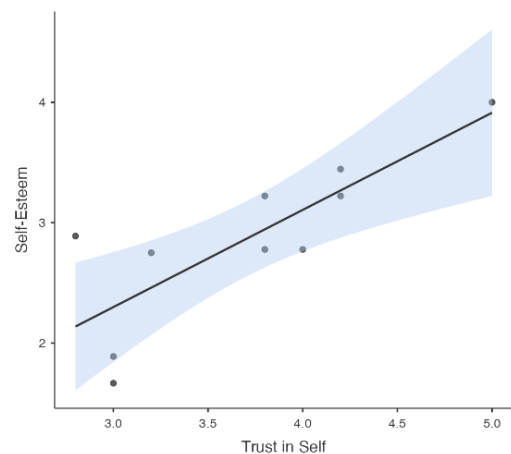


Figure 3. A scatter plot and linear regression of the Rosenberg Self-Esteem Scale (y-axis) and the Trust in Self Scale (x-axis) from 10 participants. (Pearson's $r = .76, p = .01$)

Correlation Matrix		Trust in Physician	Trust in Self	Self-Esteem
Trust in Physician	Pearson's r	—		
	p-value	—		
Trust in Self	Pearson's r	0.797	—	
	p-value	0.006	—	
Self-Esteem	Pearson's r	0.763	0.811	—
	p-value	0.010	0.004	—

Table 1. Correlational matrix exploring relationships between trust in physicians, trust in self, and self-esteem.

Finally, to further understand the relationship between trust in physicians, trust in self, and self-esteem within patients, I conducted a multiple regression analysis to test if self-esteem mediated the relationship between trust in physicians and trust in self. That is if the degree to which a patient places trust in their physician affects their trust in symptoms through its influence on self-esteem. Following the approach outlined by Baron and Kenny (1986) which prescribes testing for linear regressions for each potential relationship between the three variables to establish if individual relationships are significant and then conducting a multiple regression analysis to understand how when controlling for a variable, self-esteem, in this case, if the relationship between the two main variables falls away (Figure 4.).

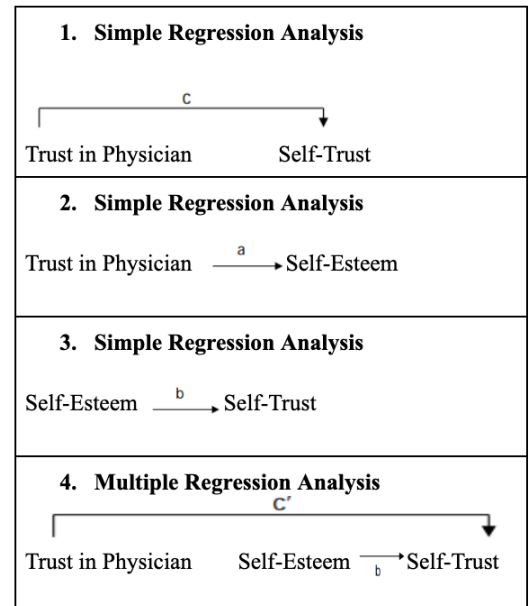


Figure 4. A visual of the regression analysis to test for mediation

I first conducted a simple linear regression analysis to determine if a patient's trust in their physician was a predictor of self-trust in symptoms. The overall regression was significant ($R^2 = .63$, $F(1, 8) = 13.9$, $p < .005$), however, not in the way that was expected. In other words, this regression suggests that similar to the correlation coefficient analysis, a patient's trust in their

physician positively predicts their trust in their symptoms ($\beta = .79, p < .005$) (Table 2). However, I had initially expected a negative relationship in that more trust in their physician would predict less trust in themselves in terms of symptoms in the context of dismissal.

Next, an additional simple linear regression analysis was used to examine if trust predicted self-esteem in patients who had experienced dismissal. The overall regression was once again significant ($R^2 = .58, F(1, 8) = 11.1, p < .05$), but again not in the way I had predicted as the results imply that a patient's trust in physicians can positively predict self-esteem ($\beta = .763, p < .05$) (Table 3.).

Then, a final simple linear regression analysis was conducted to understand if self-esteem predicted self-trust in patients who experienced dismissal. The overall regression between the two variables was significant ($R^2 = .65, F(1, 8) = 15.4, p < .05$) such that self-esteem can be understood to positively predict self-trust ($\beta = .811, p < .05$) (Table 4.)

Finally, I conducted a test for mediation to examine the relationship between trust in one's physician, self-trust in symptoms, and overall self-esteem in the context of dismissal to understand if self-esteem could be considered a mediating variable. The overall regression was not significant $R^2 = .73, F(1, 8) = 2.6, 1.99, p > .05$ and we can see that while self-esteem is also no longer significant ($\beta = .39, p > .05$) as well as trust in physicians ($\beta = .58, p > .05$) (Table 5.). We can then infer from these results that self-esteem does not mediate the relationship between trust in one's physician and trust in self.

Qualitative Analysis

Initially, I planned to conduct a thematic analysis according to the steps outlined by Virginia Braun and Victoria Clarke (Braun & Clarke, 2006), which required reviewing interview transcriptions, creating a semantic coding system for salient trends, and distilling the codes into

broader themes that appear across the interviews. While there were not enough participants for the qualitative measures to make substantial claims about common themes across individuals with endometriosis experiences, I still transcribed and organized the interview into two common themes that connect with past literature, namely: the assigning of blame over cause and ramifications of compromised trust. Although the expected pool of ten interviews would have been valuable to find common ground across patient experiences and help make generalizable inferences, this interview still provides further insight and complexity to the numeric data. Namely, it helps to extend the story of the quantitative data, even if the two stories are seemingly conflicting, and further asserts a need or use for mixed methodology in the study of dismissal. Here, I explicate several essential themes within the interview that help explain or contrast the data collected through the surveys.

Assigning Blame Over Cause: Autonomy as the Source of Pain

Perhaps one of the most startling anecdotes from the interview was an instance described by the participant in which it was not her doctor that was dismissive, but rather her nurses who claimed that the cramps and irregular cycles that she experienced were a fault of her own due to the family planning style that she chose:

“About the doctor herself I can't say I felt dismissed by her but the nurses and the medical team. The reaction at first from the nurses is that ‘no this is something you caused to yourself, maybe it’s the family planning that's why’ but the doctor herself, no, but from the nurses yes.” (Participant 1)

This patient's experience seems to exemplify epistemic gaslighting in action when considering epistemic injustice. The nurses were not only causing her to doubt herself, but taking it a step further and blamed her for the pain she was experiencing as a consequence of choosing her method of family planning. Even if it were the case that the family planning caused the pain, the blame would be on the method, not the individual. Herein this interaction lies a clear example of dismissal and unjust blame. The participants' recounting of blame was reminiscent of the lurking hysterical woman narrative of the wandering womb, yet again reminding us that although these misconstrued stories may now be rejected publicly, there is room to believe these misconceptions persist and inform medical judgments. This becomes increasingly clear as we can parse reverberations of a similar characterization of the "career women's disease" within this anecdote. Namely, that it is within the moment of a woman's exercise of autonomy over reproductive choices that is determined the cause of her suffering. While the misconception women's choices are to blame for endometriosis seemed to fade in popular media years ago, this may indicate the lasting effect that such a strong characterization can have on medical professional beliefs. She then went on to explain further how this interaction caused her to question her symptoms and believe that she was responsible for the pain she was experiencing:

At first, they made me so much believe that it was the family planning I was using and I felt like yeah I am responsible for this. I felt like even the nurses couldn't believe me" "I so much trusted the nurses because the symptoms started not long after using the family planning so at first, I thought they were making sense" (Participant 1)

This response, in particular, seems to reinforce two points: first, the emphasis on reproductive choices is at the core of pelvic pain and endometriosis and becomes a cause of blame for the individual. Second, how misattribution and blame can begin to feel like the truth within this power dynamic and make a patient question their responsibility for their own pain.

Regarding the first point of fertility, it is expected for medical professionals to assess potential events or influential factors that may be the cause for the patient's complaint, nonetheless, the recounted experience from this participant seems to take it a step further as not only is the first impulse to blame her reproductive choices but actually to blame her as a result. The career woman characterization is only one aspect of how reproductive choices and fertility is often at the forefront of doctors, researchers, and the public's mind alike when it comes to endometriosis as women with uterus' become reduced to just their reproductive body rather than being seen as a patient (Young, Fisher, & Kirkman, 2018). This was exemplified in Young, Fisher, and Kirkman's study in which they discuss the historical tradition of moralizing a woman's body when they rebel against the expectation to "take control (with their minds) of their disease (in their body) by accepting their illness, making 'lifestyle' changes, and conforming to their gendered social roles of wife and mother." (Young, Fisher, & Kirkman, 2018). By this patient choosing family planning, it may be seen as an act of rebellion by the nurses who then place moral value on this decision by blaming the patient citing her as the ultimate cause of the pain. This moralization causes us to ask, would it elicit the same response if this not been a woman and had the possible cause of symptoms not have had anything to do with the reproductive system? Context, of course, matters; however, it seems in a different case the patient would not be blamed rather the decision of family planning would be seen as an explanation for the pain rather than a value judgment.

Second, this demonstrates how instances of epistemic gaslighting further blur the patient's sense of truth and question decisions relating to their autonomy. As the participant stated, the nurses' suggestion is reasonable to a point. If the participant started the family planning process around the same time her pain started, it seems logical to include it as a possible source of the symptoms. However, what seems unreasonable is assuming that *she* is the source of her own pain. The fact that there is "blame" at all, rather than simply just a cause, exemplifies perhaps more to this encounter than searching for a diagnosis. Medical professionals should be trusted considering their training and knowledge, yet, we can question at what point these judgments blur the lines of knowledgeable authority and become instead inappropriate or transgressive. Mainly when the suggestion of the nurses implies that the patient is at fault, causing her to question the autonomy she exercised over her body.

The Lasting Ramifications of Compromised Trust

The participant went on to explain that these interactions with the nurses not only impacted the way she saw her symptoms but how the valency of the negative interaction also impacted her eagerness to seek medical help in instances of need, as she explained a feeling of hesitancy before seeking help if something goes awry:

"It made me have a distant relationship with the nurses to the point that even to this day, I don't rush to hospitals in case of anything. I'm not that person because those interactions with the doctors left me with a lot of pain." (Participant 1)

This sentiment follows findings from a study conducted by Carolyn Smith who found that experiences of "institutional betrayal" in the medical system, i.e. feeling as though the

doctor has acted counter to the interests of the patient or betrayed their trust in some way, were positively correlated with disengagement from the medical system or seeking help after the incident (Smith, 2017). This avoidance of seeking help from medical services even in dire situations seems to emphasize the depth of the emotional mark that dismissal can leave. This appears a psychologically damaging phenomenon for the patient, that they feel as though when they need help most there is nowhere to turn to, but also physically if the patient is in an immediately dangerous situation with health and does not seek help can lead to further health complications. This account is also in line with past studies that have shown that patients, particularly patients of color, often place less trust in doctors after instances of dismissal (Gonzalez et al., 2018). It is understandable that after being blamed for your own pain that one would feel a reluctance to seek medical help for fear of a similar response; however, past research also shows the danger of decreased trust and rapport between doctor and patient though it should be noted that these studies were often not conducted in the context of dismissal. More than anything, it illustrates how this blame appears to be so great that it might create emotional avoidance and fear, similar to how one might respond to situations resembling past trauma. It is the beginning of a call to action to reexamine the conduct that occurs within the interaction. Ultimately, the goal of medical care is to seek solutions, and it appears that this dismissal might only alienate patients making it harder to achieve the care they deserve. As this was only one interview, it is not enough to know if this is a recurring theme across patients with endometriosis but given the high negative valence this interaction seemed to have on the patient, it seems an important piece to keep in mind.

Interestingly, this information tells the opposite story of the regression analysis and rather is consistent with the hypothesis that more trust in physicians, i.e., believing them when they said

the pain was her fault, resulted in less self-trust in her symptoms and a lower sense of self-esteem. Despite this contradiction, it is not enough data to make a clear case against the quantitative data but rather shows that there is a call here for further investigation in order to understand the direction and full scope of the impact. These two findings imply that there does seem to be an impact of doctor dismissal. However, the direction of this relationship and its saliency remains unclear and requires further and expanded research to fully understand the dynamics at play.

Discussion

At the outset of this study, I anticipated a relationship between self-trust of symptoms and a patient's trust in their physician such that higher levels of self-trust would indicate a lower sense of trust in physicians making self-trust not a predictor of trust in physicians. Though my hypothesis was not supported, from the Pearson r correlation and multiple regression analyses, we can identify relationships between the variables. Contrary to my hypothesis, among patients who felt dismissed, greater trust in self correlated with trust in their physician and self-esteem as was trust in physicians with self-esteem. Implying that in the context of dismissal patients with higher trust in physicians are also likely to have higher trust in their symptoms though this relationship is not mediated by self-esteem. Even with these significant findings, causal relationships cannot be assessed nor can we say with certainty that these findings would replicate due to the low sample size of the study.

Perhaps the most curious of the findings is the positive correlation between trust in physicians and trust in self which suggests that as the patient puts higher trust in the physician, they are likely to have a higher sense of trust in themselves, particularly in their symptoms. This finding might make sense if not in the context of dismissal, meaning that if a doctor is providing

non-dismissive feedback and validating the patient, it would make sense that this either causes or coincides with a heightened self-trust. This might lead us to speculate about the clarity of the questionnaire; while participants were instructed to consider the survey questions in the context of a doctor that dismissed them, it is possible this remained unclear or unnoticed. This seems especially likely after the limited qualitative data; however, given there was only one interview, it could be possible that other interviews might suggest that they felt at once high trust in doctors and themselves which highlights the importance of needing to gather more data before making any inferences about the meaning of the data.

Some may find the results from the qualitative data to be surprising, however, the treatment the participant received from the nurses seems to actually fall in line with past findings from interviews with nurses which can help to speculate the reasons for which this response was provided. A qualitative research study revealed that several of the nurses working in the gynecologic of a hospital made many references to how upon first interactions with endometriosis patients they appear to be experiencing pain that is psychosocial or somatic or that they felt they did not have enough of an understanding of endometriosis to fully understand or sympathize with the patient's experience (Bach et al., 2016). Though it is impossible to know the specific reasoning behind the specific encounter between the participant and her nurses, given the lack of knowledge or training in endometriosis in the medical system (van der Zanden et al., 2021; Bach et al., 2016; Guidone, 2020). it seems likely. If this is the case, it seems to boost awareness, training, and advocacy is one of the best ways to combat the perpetuation of these misconceptions but future research is necessary before any action can be taken.

Strengths

Though there are sizable drawbacks to these findings, it is also worth noting what this study and these findings contribute to the field of research on dismissal. Given the narrow pool of literature studying dismissal, particularly from a patient-centered focus or centering endometriosis, this study is an important first step in broadening the scope of research on this pertinent issue. Much work must be done to specify the relationships suggested by the results of this study, yet, the subtle tension that exists between the quantitative and qualitative data suggests that there *is* a relationship between trust and dismissal that must be further investigated.

Speaking to the methodology, while using a mixed-methodology for this study was an ambitious approach considering the constraint of resources and time it ultimately was successful in collecting a variety of data to weave together a narrative that is as complex and varied as its subject matter. Because a study of this nature has not been done in this particular form, there is novelty in this study's approach and future studies with greater resources might consider a similar methodology in order to accurately capture the experience of dismissal.

Limitations

While the data analysis may have found significant results for two of the regressions, it is imperative to consider these results in the context of the material. One of the most notable limitations is the small sample size, particularly regarding the qualitative measure meaning that we cannot make claims on behalf of the results. Despite contacting a surplus of online groups, the response rate was low, a greater sample size, particularly for the qualitative measure, would have helped generate more rich data to help tell the story of the quantitative data and help understand what similarities occur between patients with endometriosis who have experienced dismissal. In considering a larger sample size, another component that must be kept in mind is the homogeneity of the sample given only nine out of the 10 included participants reported

themselves as white. As explained in the literature review, this is an issue that affects patients differently depending on race, gender, and socioeconomic status (Chatman, 1976; Armstrong et al. 2007; Gonzalez et al., 2018). This suggests that the stories captured by this data cannot be generalized or decided to be accurate to the stories of all patients who have been dismissed. While I prioritized reaching out to groups that had a diverse population during recruitment, future research should continue to prioritize collecting a non-WEIRD (White, Educated, Industrialized, Rich, and Democratic) sample in order to ensure the generalizability and external validity of the findings.

Because the sample is limited to only one group: patients who have been dismissed, there is no group to compare these findings making it impossible to stake any causal claims. Though I conducted the comparison to the Likert Scale midpoint, there is no way to know the differences in scores and their significance without collecting data from different groups. These comparison groups could either be patients who have experienced dismissal or for a more narrow look at how trust functions within dismissed patients-patients who believed their doctors were telling the truth vs patients who did not believe the dismissal they received. With only the quantitative data of the study in mind, one might predict that there is no difference in the degrees to which patients trust their physicians and themselves whether they have been dismissed or not. However, considering the quantitative data and qualitative data, along with my original hypothesis, I might argue that there would be a difference in trust levels in physicians and self between the two groups if approached in a slightly different manner. I cannot say with certainty that within a group of patients who have experienced dismissal that trust would differ significantly for those who accepted dismissal as true versus those who rejected dismissal but I might hypothesize that there is no difference in trust in physicians but perhaps slightly greater trust in self. While these

hypotheses cannot be fully formed based on the data alone, it adds to the need for expanded research. Although exploring correlative claims is helpful during the first steps of this kind of research, in the future, utilizing an approach that would require statistical analysis to make causal inferences may be more useful to make more substantive conclusions.

Further Directions

From what we can glean from the results, the conflicting results prompt a need for further research. The first step seems to be a similar study utilizing a larger sample size to ensure for enough qualitative or quantitative data. Future research might focus on two existing in-person support groups and establish a relationship with the facilitator to ensure a robust response rate.

However, extending beyond the limited sample for this study, we might consider future directions to build upon this study if these same results were found in a larger sample. In past research, it seems as though one central point medical professionals seem to focus on is how endometriosis impacts not the patient themselves but those around them, i.e. significant others, family members, coworkers, etc. (Bach et al., 2016; Young, Fisher, & Kirkman, M., 2019).

While this may appear dismissive to the patient with endometriosis in general, it might be worth gathering an understanding of the extent of support in their personal lives and how much this impacts their sense of trust. For example, a patient may be more likely to believe their doctor's dismissal if there is not an additional figure from their support system offering encouragement or suggesting seeking another perspective. Conversely, one might speculate that someone without such a resource might be more likely to have a lesser sense of self-trust. All to say that this may be another missing piece of the puzzle to consider when attempting to interpret the conflicting results from the current study and an important area for future consideration.

In reviewing the high correlations, specifically between trust in physicians and trust in self, one alternative explanation may be that the survey was capturing how trusting a participant was rather than capturing trust in the particular dynamic of dismissal between physician and patient. To mitigate this, it seems worthwhile that future studies may include an additional variable of general trust to understand the extent to which someone may simply be a trusting person and where this trust may or may not deviate when evaluating trust in relation to their symptoms and experience of dismissal with physicians. Introducing this concept of general trust would help create more specific and substantial claims as to what phenomenon is specific to dismissal instead of how trusting that person may naturally be which may have been the case in this study.

From the qualitative research, one interesting theme that can be found was the discussion regarding the emphasis on the reproductive system and fertility can turn to finding the source of pain into a blame game that lands on the patient rather than searching for a cause without emotion or blame in any direction attached to it. Fertility is a key component in getting doctors to listen or dismiss, and generally when it comes to reproductive health is a tricky subject, past research has shown the complicated relationship between fertility and endometriosis in terms of dismissal. (Young, Fisher, & Kirkman, 2018, Carpan, 2003) Future research might incorporate more questions on this relationship and further understand the complexities of fertility and the reproductive body's relevance as a facet of endometriosis. Another compelling piece of this research seems to be the idea of these lasting narratives of hysteria, endometriosis being a "career woman's disease" which might contribute to stereotyping. It may be beneficial if future research pursues to what extent these stereotypes are implicit within the patients with endometriosis themselves and how this might impact the trust of their symptoms and doctors.

Considering impactful past work on stereotype threat, we might consider if this characterization of career woman's disease is no longer prevalent or if we can find stereotype threat in patients undergoing the diagnostic process.

Conclusion

While we cannot make any substantive claims from the results found in this current study due to the limited sample size and the possibility of confusion in the study materials, the conflicting stories that exist between the quantitative and qualitative data are certainly enough to incentivize further research and exploration. However, limitations aside, the stories told in the quantitative and qualitative data weave a narrative as complex as the history of patients seeking a diagnosis for endometriosis. As was explained, much mystery and conflicting narratives seem to shroud women's health, and to achieve reliable and generalizable conclusions, great care must be taken in research, however, I strongly believe that this work is a substantive step in the right direction. It is one of the first studies to utilize both quantitative and qualitative data collection to center on the experience of the patient which from this study appears as a useful way to gather a wide range of data to capture a complex phenomenon. The survey data implies that there is an important relationship between doctors, patients, and trust does seem to be a variable of interest within this dynamic but more research is needed to further specify its functionality. The qualitative data helps to conceptualize the nature and impact of dismissal at a more detailed level and signifies that there may be significance to the theory that these wandering misconstrued narratives that have followed endometriosis have a direct impact on the diagnostic process and consequently on the patient. Although the current research perhaps poses more questions than answers, it is a useful step in rewriting the narratives surrounding endometriosis. At a juncture in which the underlying narratives of wandering wombs, hysterical women, endometriosis as a

career women's disease, and many more stories gathered over the years cloud the diagnostic process, it only further implores this winding story to turn its attention to the main truth that must be heard: the patients.

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Tables

Model Fit Measures

Model	R	R ²
1	0.797	0.634

Omnibus ANOVA Test

	Sum of Squares	df	Mean Square	F	p
Trust in Physician	2.75	1	2.754	13.9	0.006
Residuals	1.59	8	0.198		

Note. Type 3 sum of squares

[3]

Model Coefficients - Trust in Self

Predictor	Estimate	SE	95% Confidence Interval		t	p	Stand. Estimate
			Lower	Upper			
Intercept	0.676	0.824	-1.223	2.58	0.821	0.435	
Trust in Physician	0.919	0.247	0.350	1.49	3.727	0.006	0.797

Table 2. Displays the relationship between trust in physician and trust in self

Model Fit Measures

Model	R	R ²
1	0.763	0.582

Omnibus ANOVA Test

	Sum of Squares	df	Mean Square	F	p
Trust in Physician	2.50	1	2.500	11.1	0.010
Residuals	1.80	8	0.225		

Note. Type 3 sum of squares

[3]

Model Coefficients - Self-Esteem

Predictor	Estimate	SE	95% Confidence Interval		t	p	Stand. Estimate
			Lower	Upper			
Intercept	-0.0175	0.876	-2.039	2.00	-0.0200	0.985	
Trust in Physician	0.8758	0.262	0.271	1.48	3.3367	0.010	0.763

Table 3. Displays relationship between trust in physician and self esteem

Model Fit Measures

Model	R	R ²
1	0.811	0.658

Omnibus ANOVA Test

	Sum of Squares	df	Mean Square	F	p
Self-Esteem	2.86	1	2.855	15.4	0.004
Residuals	1.48	8	0.186		

Note. Type 3 sum of squares

[3]

Model Coefficients - Trust in Self

Predictor	Estimate	SE	95% Confidence Interval		t	p	Stand. Estimate
			Lower	Upper			
Intercept	1.365	0.611	-0.0425	2.77	2.24	0.056	
Self-Esteem	0.815	0.208	0.3359	1.29	3.92	0.004	0.811

Table 4. Explores the relationship between self-esteem and self-trust

Model Fit Measures

Model	R	R ²
1	0.856	0.734

Omnibus ANOVA Test

	Sum of Squares	df	Mean Square	F	p
Self-Esteem	0.430	1	0.430	2.60	0.151
Trust in Physician	0.328	1	0.328	1.99	0.202
Residuals	1.156	7	0.165		

Note. Type 3 sum of squares

[3]

Model Coefficients - Trust in Self

Predictor	Estimate	SE	95% Confidence Interval		t	p	Stand. Estimate
			Lower	Upper			
Intercept	0.685	0.752	-1.093	2.46	0.911	0.393	
Self-Esteem	0.489	0.303	-0.228	1.21	1.613	0.151	0.487
Trust in Physician	0.491	0.348	-0.333	1.31	1.409	0.202	0.425

Table 5. Explores the relationship between trust in self, self esteem, and trust in physician.

One Sample T-Test

		Statistic	df	p	Mean difference		Effect Size
Trust in Physician	Student's t	1.525	9.00	0.162	0.290	Cohen's d	0.482
Trust in Self	Student's t	3.188	9.00	0.011	0.700	Cohen's d	1.008
Self-Esteem	Student's t	-0.623	9.00	0.549	-0.136	Cohen's d	-0.197

Note. $H_a \mu \neq 3$

Descriptives

	N	Mean	Median	SD	SE
Trust in Physician	10	3.29	3.64	0.602	0.190
Trust in Self	10	3.70	3.80	0.694	0.220
Self-Esteem	10	2.86	2.83	0.691	0.219

Table 6. Results of the One-Sample t-test comparing the scores of trust in physician, trust in self, and self-esteem with the Likert Scale mid-point of three as reference

Appendix A.

IRB Approval

Bard College

Institutional Review Board

Date: January 25, 2022

To: Isabella Pihas

Cc: Kristin Lane, Deborah Treadway, Brandt Burgess

From: Tom Hutcheon, IRB Chair

Re: How Physician Dismissal Impacts the Self-Trust of Endometriosis Patients

DECISION: APPROVED

Dear Isabella,

The Bard Institutional Review Board has reviewed your revisions and approved your proposal entitled, "How Physician Dismissal Impacts the Self-Trust of Endometriosis Patients." Your proposal is approved through January 25, 2023 and your case number is 2022JAN25-PIH.

Please notify the IRB if your methodology changes or unexpected events arise.

We wish you the best of luck with your research!



Tom Hutcheon, Ph.D.

IRB Chair

Assistant Professor of Psychology

Bard College

thutcheo@bard.edu

Appendix B.

Recruitment Script

Hello,

My name is Isabella Pihas, I'm a senior at Bard College studying psychology currently completing my thesis. I'm conducting a study to explore the difficulties in diagnosing endometriosis and how that affects the patient's sense of self and their symptoms. I'm currently looking for participants who have been diagnosed with endometriosis and are willing to share their perspectives. The study is in two parts, the second part is optional. The first portion only takes 10-15 minutes at most and is an online survey assessing their feelings about the diagnostic process, the second part is an optional interview that can last up to an hour and will be conducted on zoom for anyone interested which they can indicate at the end of the survey. Participants will receive compensation for their time equivalent to minimum wage (\$2.50 for participating in the survey component, \$15 for the interview component) If this is something you think anyone in your group would be interested in participating in, I would greatly appreciate you passing this email on.

For anyone interested, this is the study link: [insert study link here] This study is being supervised by Kristin Lane, Associate Professor of Psychology, and has been approved by Bard's Institutional Review Board.

Thank you for your time!

Isabella Pihas

Appendix C.

Quantitative Informed Consent Agreement

INFORMED CONSENT AGREEMENT

Title: Experiences With The Medical System

Principal Investigator: Isabella Pihas

Institution: Bard College

Background: In the current research study, I am interested in the varied experiences of patients with endometriosis when trying to obtain a diagnosis and how that relates more broadly to how they see their symptoms.

What you will do in the study: You will fill out a short questionnaire online that asks questions about your experience with doctors and your own perception of endometriosis. This survey will take approximately 10-13 minutes.

Risks and Benefits: Because talking about one's symptoms and experiences with health are potentially traumatic, some participants may find this difficult. Some participants may find it empowering to share their stories and may take comfort in being heard in some capacity.

They may also receive indirect benefits from being a part of research that contributes to a field that focuses on patients'; rights and empowerment. It is the hope that participants will take comfort in knowing that they have contributed to a sparse but necessary field of research that will hopefully increase awareness and change for patients.

Compensation: In exchange for participating in the experiment, you will receive a payment of \$2.50 through Venmo or PayPal. It is to be noted that in order to receive compensation, you will need to provide your PayPal or Venmo information, though the information will be deleted after compensation.

Your rights as a participant: Your participation in this experiment is completely voluntary, and you may withdraw from the experiment at any time without penalty. In the online questionnaire, you may withdraw by simply closing the computer browser.

Confidentiality: You will not provide your name in this study and we will not know the identity of any participant except for information given for compensation (i.e. Venmo/Paypal usernames) or potentially an email address if participants decide to opt into an optional interview which will be described in detail later in the study. Any information from participants (i.e. compensation information or email addresses) will be collected and stored separately from the questionnaire responses and destroyed immediately after compensation making this study confidential but not wholly anonymous. In order to receive compensation, you must leave your compensation information. Data from the study may be posted (without any identifying information) at the Open Science Framework.

Agreement: The nature and purpose of this research have been sufficiently explained and I agree to participate in this study. I understand that I am free to withdraw at any time without incurring any penalty.

If you have questions about this study, please email ip2964@bard.edu or Kristin Lane the advisor for this project at lane@bard.edu. If you have questions about your rights as a research participant, please contact the Bard College Institutional Review Board: irb@bard.edu.

By checking the box below, I am indicating that I am in agreement with the above statement of consent.

- I am at least 18 years of age and provide my informed consent to participate in this survey
- I am not 18 years of age and do not provide my informed consent to participate in this survey

Appendix D.

Qualitative Informed Consent Agreement

INFORMED CONSENT AGREEMENT

In the current research study, I am interested in the varied experiences of patients with endometriosis when trying to obtain a diagnosis and how that relates more broadly to how they see their symptoms.

What you will do in the study.

You will discuss your experiences with the medical system with an interviewer.

Risks and Benefits.

Because talking about one's symptoms and experiences with health are potentially traumatic, some participants may find this difficult to discuss or relive. Sometimes when sharing details about traumatic events or difficult subjects, people find themselves experiencing a sort of emotional "hangover" that often subsides but is something to be mindful of following the interview. Participants have the agency to share however much or little information they are comfortable with and can pause or stop at any time.

That said, some participants may find it empowering to share their stories and may take comfort in being heard in some capacity. They may also receive indirect benefits from being a part of research that contributes to a field that focuses on patients' rights and empowerment. It is the hope that participants will take comfort in knowing that they have contributed to a sparse but necessary field of research that will hopefully increase awareness and change for patients.

Audio Recording of Interview.

In order to analyze the data from the interview, I will need to audio record the interview and/or take notes during it, you will have the choice of whether or not you consent to the interview being audio recorded. This recording, though, will not contain any identifying information such as name or other potential identifiers. All audio recordings and notes will be protected in a password-protected file on my personal computer.

Compensation.

No identifying information will be reported in the study and any specific reference to the interviews will be done using a pseudonym. Compensation information, ie. Venmo/Paypal usernames will be stored separately from the questionnaire responses and destroyed immediately after compensation as will email addresses. In exchange for participating in the experiment, you will receive a payment of \$15 through Venmo or Paypal.

Your rights as a participant. Your participation in this experiment is completely voluntary, and you may withdraw from the experiment at any time without penalty. At any point during the interview you may ask to take a pause, can refrain from answering any questions, or can ask to end the interview and not be included in the data. If you choose to consent to the recording of audio, you have 48 hours after the interview to request to withdraw consent and have the audio destroyed.

Contact: If you have questions about this research, please contact Isabella Pihas at ip2964@bard.edu

Confidentiality.

Data from the study may be posted (without any identifying information) at the Open Science Framework. Agreement. The nature and purpose of this research have been sufficiently explained and I agree to participate in this study. I understand that I am free to withdraw at any time without incurring any penalty. I certify that I am at least 18 years of age. If you have questions about this study, please email Isabella Pihas at ip2964@bard.edu or Kristin Lane the advisor for this project at lane@bard.edu. If you have questions about your rights as a research participant, please contact the Bard College Institutional Review Board: irb@bard.edu.

By checking the box below, I am indicating that I give consent to the interview being recorded

- I provide my informed consent for the interview to be audio recorded
- I do not provide my informed consent for the interview to be audio recorded

By checking the box below, I am indicating that I am in agreement with the above statement of consent.

- I am at least 18 years of age and provide my informed consent to participate in this survey
- I do not provide my informed consent to participate in this survey

Appendix E.

Prescreen

What is your age? _____

Have you been diagnosed with endometriosis: _____

Write any additional illnesses you may have: _____

Have you experienced dismissal from a doctor? i.e.. Says the pain is exaggerated, said it was just normal period pain, made you feel belittled/silly/hysterical, etc. Yes No Don't Know

Appendix F.

Demographics

What is your gender? Male Female Non-Binary Other Prefer not to say

What is your race? American Indian or Alaska Native Native Hawaiian or Pacific Islander White Black or African-American Asian Other Prefer not to say

What is your ethnicity? Hispanic or Latinx or Spanish Origin Not Hispanic or Latinx or Spanish Origin

How much do you agree with the following statement: I feel confident that I have a deep understanding and knowledge of endometriosis and any other health concerns I may have.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree Prefer not to say

Appendix G.

Trust in Physician Scale

Trust In Physician Scale

1. I doubt that my doctor really cares about me as a person.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

2. My doctor is usually considerate of my needs and puts them first

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

3. I trust my doctor so much I always try to follow his/her advice

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

4. If my doctor tells me something is so, then it must be true.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

5. I sometimes distrust my doctor's opinion and would like a second opinion.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

6. I trust my doctor's judgments about my medical care.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

7. I feel my doctor does not do everything he/she should for my medical care.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

8. I trust my doctor to put my medical needs above all other considerations when treating my medical problems.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

9. My doctor is a real expert in taking care of medical problems like mine.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

10. I trust my doctor to tell me if a mistake was made about my treatment.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

11. I sometimes worry that my doctor may not keep the information we discuss totally private.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

Appendix H.

Self-Trust in Symptoms Scale

1. I felt confident that my symptoms are real.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

2. I understood my body more than my doctor.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

3. I trusted that the symptoms that I was experiencing were legitimate.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

4. I knew my body better than my physician.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

5. My symptoms are what I think they are.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

6. I questioned if my symptoms were real

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

Appendix I.

Rosenberg Self-Esteem Scale

Below is a list of statements dealing with your general feelings about yourself. Please indicate how strongly you agree or disagree with each statement.

1. On the whole, I am satisfied with myself.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

2. At times I think I am no good at all.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

3. I feel that I have a number of good qualities.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

4. I am able to do things as well as most other people.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

5. I feel I do not have much to be proud of.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

6. I certainly feel useless at times.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

7. I feel that I'm a person of worth, at least on an equal plane with others.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

8. I wish I could have more respect for myself.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

9. All in all, I am inclined to feel that I am a failure.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

10. I take a positive attitude toward myself.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

Appendix J.

Interview Protocol

Introductory Questions

How old are you?

How old were you when your symptoms first appeared?

What were the first symptoms you experienced of endometriosis?

Let's talk about your diagnosis, how old were you when you received one?

-What was the diagnostic process like for you?

What was the diagnostic process like, what difficulties or support did you experience?

What does your support system look like, outside of the healthcare system?

Features of dismissal

AIM: Trying to understand the variation of dismissal, how much they agreed or disagreed with the dismissal

Let's talk about your experiences with doctors before endometriosis, can you tell me about some of the interactions with your doctors and how it made you feel before developing endometriosis?

Can you describe how you felt towards the medical field before developing endometriosis?

Now can you tell me if there were any changes to that experience once you started

seeking help for endometriosis?

What was the response from doctors when you reported your symptoms for endometriosis?

Can you tell me about the first time you felt dismissed by a doctor?

If you remember, what were your immediate reactions to that at the moment, and following the appointment.

How much did you believe what the doctor was saying? Did it make sense to you?

Feelings of empowerment/disempowerment

AIM: Trying to understand the amount of agency that patients feel they have after experiencing dismissal from doctors

After the experiences with your doctor [if they discuss dismissal from their doctor], how did you feel about sharing your experience going forward?

When you experienced dismissal, did that change the extent to which you felt you could speak freely or advocate for yourself with your doctor? If so, how, if not, why?

Can you tell me a time when a doctor made you feel heard and felt like you could speak freely and with authority?

Can you think of a time when you felt you didn't feel heard or had no say in making decisions about your health trajectory?

Self-Trust

Aim: Understanding how dismissal might affect the way one trusts their symptoms over a doctor's (dismissive) suggestions.

After that instance of rejection, how did that affect the way you thought of or trusted your Symptoms?

[IF YES] Were there instances when you feel that mistrust of your symptoms spread to other areas of your life? If so, can you share an example?

[If accepted dismissal] How did you come to trust your symptoms rather than the doctors?

[If rejected dismissal] Can you tell me about the decision to not agree with your doctor and listen to your symptoms? What did that feel like? Did you receive pushback?

Self-Image

Aim: Does doctor dismissal spread to other areas of life

After a doctor's appointment in which you were dismissed, how did that make you feel about yourself?

Can you tell me about the emotional experience of receiving a formal diagnosis and knowing that your instincts were right?

Thinking back to your experiences with doctors and endometriosis, can you tell me if there's anything you have learned about yourself or the healthcare system?

Can you tell me about how you continued on in your health journey despite facing dismissal?

Outcome/Conclusion

How do you feel like your treatment trajectory might have been different had you not been dismissed?

Knowing what you know now, are there ways you would have liked your doctor to have done differently, or do you feel there are ways you might have interacted with them differently?

Is there anything you were surprised that I didn't ask?

Appendix K.

Survey Debrief

Thank you for participating

INFORMATION ABOUT THE CURRENT RESEARCH

The primary goal of this study was to understand the effects of dismissal from doctors on the patient when they either believe that dismissal to be true or false. I define dismissal here to mean that a doctor doesn't take their patient's concerns and testimonies of illness to be serious and either offer responses that invalidate the patient's experience or deny there is a problem when there really is. Dismissal in this sense is not a doctor simply saying they have exhausted all options and give recommendations for other doctors, rather a disinterest in pursuit treatment options or further possibilities due to their disbelief. I hypothesize that patients who accepted dismissal as true will have lower trust in their symptoms. This study will hopefully give insight into the nature of dismissal and how it impacts the patient's experience. As well as help to potentially generate ideas of how to establish resources for patients. Due to most of the existing research on doctor dismissal focusing only on doctors, rather than patient perspectives, I thought it important to add patient perspectives to this dialogue. Your participation is a helpful first step in expanding the field of research on medical dismissal.

CONFIDENTIALITY

All information from the consent form was accurate and you may still choose to withdraw from the study with no penalty. Due to the fact that the purpose of the study is sensitive to the information given by participants, please do not share this debriefing form or any information about the study with anyone else you may know who is taking this study, as this

could negatively impact the results. If you have any questions, concerns, or would like to learn more about the study and its results, contact Isabella Pihas at ip2964@bard.edu or the advisor for this research Kristin Lane at lane@bard.edu. If you have any questions about your rights as a participant, contact the Chair of the Institutional Review Board, Bard College at irb@bard.edu.

Thank you again for your participation in this study