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A Phenomenological Approach to Understanding Different Perceptual Interests: Interactions Between Endometriosis Patients and Their Physicians

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Abstract

Understanding patients' experiences of illness is critical to successful and holistic treatment. It is especially important in illnesses associated with diagnosis delays and mismanagement, like endometriosis. Endometriosis affects ten percent of reproductive age females globally but remains poorly recognized due to a lack of understanding from society and the healthcare system, an under-appreciation of women's pain, and stigmatization. The broader structural implications of the paucity in research and physician training reveal neglect of patient embodiment and denial of women's pain within medicine. By focusing on the history of endometriosis, the way it has been conceptualized through patient and physician perspectives, and the way it is part of a larger history of dismissing women's pain, we examine the ways in which a phenomenological approach bridges the differences in perception between patient and physician as well as patient and society.

Keywords: Endometriosis, phenomenology, women's pain, gender bias, feminist health studies

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Introduction

Understanding patients’ experiences of illness is critical to successful and holistic treatment. It is especially important in illnesses that are shrouded in misinformation and often mismanaged, such as endometriosis. Endometriosis affects ten percent of reproductive age females globally; however, despite its high prevalence, there is often a delay of four to 11 years between the onset of symptoms to surgical diagnosis (World Health Organization, 2023; Nielsen et al., 2023, p. 1039). Women with the condition experience life-impacting pain, heavy menstruation, and infertility, amongst a myriad of variable and non-specific symptoms. Though common, endometriosis is poorly recognized. The variation in its presentation is somewhat responsible for the condition being inconsistently diagnosed over history. But it is also partially misunderstood because of clinical disinterest, both on an individual and institutional level. In what follows, we investigate both doctors’ perspectives, including that of Dr. Huang[3], and patient testimonies from recent literature. By focusing on the history of endometriosis, the way it has been conceptualized, and the way it is part of a larger history of dismissing women’s pain, we examine the ways in which a phenomenological approach bridges the differences in perception between patient and physician as well as patient and society.

Dr. Huang recalls encountering a patient with endometriosis and experiencing firsthand the disconnect between physician and patient perspective. She reflects:

> I first learned about endometriosis during a general practice (family doctor) placement in medical school. Jane[4] was a female patient in her mid-30s, married with a four-year-old son, who worked as a primary school teacher and loved hiking in the Scottish Highlands. She was recently diagnosed with endometriosis, and my supervisor encouraged me to take a detailed medical history from Jane. At the time, endometriosis existed only as a theoretical concept to me, one that I had briefly read about in textbooks but not been taught in lectures. I understood that it occurred when tissue normally found in a specific part of the body (the uterus) grows outside of it. Instead of shedding every menstrual cycle as it does in the uterus, abnormally placed uterine tissue builds up, leading to inflammation, scarring and painful cysts, occasionally even causing reproductive organs to stick together.
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> Before I spoke with Jane, I read through her medical notes, and was surprised by the number of appointments, investigation results, changed diagnostic codes, and referrals she had before she was finally diagnosed two and a half years after her initial presentation with symptoms. In one of her earlier medical entries, the doctor who saw her wrote, “Impression: PMS (premenstrual syndrome), likely stressed over toddler with sleep regression.” Under “Plan,” he documented, “advised simple analgesia; consider referral to mental health nurse practitioner.” He did not perform a pelvic examination, convinced after several minutes of questioning that her symptoms must be related to the stresses of being a mother. On the other hand, Jane’s account of her lived experience was drastically different. She was feeling low and stressed, not because she was not getting enough sleep, but because her pain was often debilitating, leaving her bed-bound, unable to run after her active toddler or go to work; her periods were so heavy that she once missed a flight because she was unable to leave the bathroom stall, and she had to give up her love of hiking. Above all else, Jane was frustrated and confused by her inability to conceive again. How was there such a

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disconnect between the doctor’s understanding of Jane’s symptoms and Jane’s lived experience of them?

The disconnect between patient and physician can partially be explained by the historical conception of an endometriosis diagnosis, which has long been reduced to psychological symptoms and devalued by modern medicine in favor of physical ailments. In “Wandering Wombs and ‘Female Troubles:’ The Hysterical Origins, Symptoms, and Treatments of Endometriosis,” Cara Jones (2015) writes that there has been much uncertainty and debate among scholars regarding the discovery and first references to endometriosis in medical literature. Among other interpretations, its symptoms have been thought to overlap with the historic and misogynistic diagnosis of hysteria. Just as endometriosis is categorized by the movement of uterine tissues outside of the uterus, the ancient Greek conception of hysteria has to do with the notion of the “wandering womb.” The womb was believed to travel throughout women’s bodies, causing excessive emotion, or hysteria. By aligning the womb with hysteria, any symptoms associated with the uterus are considered to be a product of the mind, something illogical, without any biological basis. To this day, physicians often feel intimidated by the complicated presentation of endometriosis, and attribute the unpredictability of the illness to the patients themselves, labeling them difficult or mad - a vestige of the hysterical woman discourse (Young, 2018, p. 346).

This misunderstanding about the etiology of endometriosis corresponds to the Cartesian mind/body split, which is foundational to the practice of modern medicine. According to this framework, the mind and body are two separate entities: the body is something passive that functions mechanically and requires observation, and the mind is the more active element that is representative of the person themself. In “Medicine and Paradigms of Embodiment,” Drew Leder (1984) describes how in the typical clinical encounter, there is an incongruence between the patient’s and physician’s perception of the interaction. The patient presents her lived-body for treatment, aware of the way in which her existence in the world informs her illness. The practitioner, however, treats the Cartesian body, ignoring the lived and embodied perceptual aspects. In the case of endometriosis, when its symptoms are misunderstood as a figment of the patient’s imagination, there is no body on which the physician can focus treatment. Endometriosis becomes something fantastical, like hysteria, and loses the credibility that modern medicine privileges.

Though endometriosis is not just a figment of women’s imagination, its enigmatic status is in part a result of a willful ignorance about its pathophysiology. Today, endometriosis is still considered a complicated condition because “there is no known cure, the cause is unclear, and the efficacy of treatment varies greatly from patient to patient” (Whelan, 2007, p. 957). This lack of information has built an air of mystery around the condition. Additionally, the vast array of symptoms attributed to endometriosis means that it was once thought to be multiple disorders and still goes misdiagnosed today. One reason for this is that pain is subjective and can be difficult to assess by medical providers. Clinicians regularly rely on standardized scales to determine their patients’ level of pain. A group of UK-based researchers explored what patients and clinicians each considered challenging and effective in endometriosis pain communication (Bullo & Weckesser, 2021). They found that standardized pain scales (such as the Numeric Rating Scale) were an “ineffective (standalone) tool due to the subjectivity of pain and inability of such scales to capture qualitative aspects of pain” (Bullo & Weckesser, 2021, p.5). This model is fundamentally flawed, however, given that a numerical scale is merely a thin description of the patient’s being-in-the-world. The patient’s experience, on the other hand, is necessarily “thickened” (Geertz, 1973) by the unseen and nuanced part of their lives. In Bullo and Weckesser's study, both patients and clinicians felt that descriptions of the quality, location, and impact on daily life of pain were more effective in communicating pain symptoms, all of which would be considered when clinicians adopt a phenomenological approach. This is supported by the researchers, who advocate for further research and novel methods on effective pre-diagnosis patient-clinician communication of pain.

Discrepancies between patients' and providers' perceptions of the encounter extend beyond pain alone. This is perhaps unsurprising, given the nature of perception. This perceptual difference between patients and their providers can be understood through the field of phenomenology. In "The Art of Perception: From the Life World to the Medical Gaze and Back Again," Hick (1999) notes that in some cases, the difference between patient and physician is so vast that "there is not much common ground left between the two" (p. 129). More recent analyses, including "Phenomenology and its Application in Medicine," similarly point to the difference between patient and physician perceptions. Carel writes that "this gap between the third and first person experiences of illness is not a difference in knowledge level but a difference in the approach to illness. So when a patient and clinician are discussing the patient's condition, there is often no shared set of assumptions or a common understanding of the object of discussion, the illness" (Carel, 2010, p.42). As Carel notes, the difference in perception does not have to do with the physician's extensive education. Instead, it has much more to do with individuality. Though we all experience the same reality, none of us perceive it in the same way: "There are no such things as universal objects of perception, given conclusively and in the same way to all of us" (Hick, 1999, p.132). Instead, we all have different identities, experiences in the world, and "perceptual interests" that guide our individual recognition (Hick, 1999, p.132).

Carel expands upon the way that physicians and patients see things differently. Medicine views illness in objective and strictly physical terms. But the patient, on the other hand:

> experiences her illness from within, as a transforming experience impacting all dimensions of life. She experiences her illness as a disruption of her previous lived experience; this includes bodily alienation, an altered experience of space and time, frustration of bodily intentionality, social changes, and challenges to self identity and integrity. She does not compartmentalise the disease, nor does she understand it solely as a set of physical symptoms. Rather, for her, the illness is an ongoing presence that modifies her life. The impact is not only physical but also psychological, social, cognitive, emotional, existential, and temporal. (Carel, 2010, p.42).

This naturally poses a dichotomy: illness can either be viewed from a naturalistic lens or from a deeply personal one. If both parties in the clinical encounter approach it from these vastly different perspectives, it may seem like there is no hope for understanding.

Hick suggests that there may be another way forward, however. He imagines a third option, in which "scientific perception patterns can and must be completed by perception patterns more adequate to the open life world of an ill patient" (Hick, 1999, p.136). This presents a more balanced approach to the practice of medicine, one that attends to both the science and lived experience of illness. Hick (1999) advocates for physicians to engage in "perceptual exercises" by "trying to look beside petrified structures, making an effort to overlook the evident, aiming at discovering the margins and horizons of the obvious, reactivating unlearned perceptive movements," which ultimately lead to the "discovery of new sense, thereby providing a fresh starting point for reconsidering the problem at hand" (p.137). This novel methodology offers providers the opportunity to be taught by their patients and treat them according to their individual needs. These recommendations are especially apt when considering medical perception in relation to poorly understood and incurable conditions like endometriosis.

Hick elaborates by providing specific examples in which this can be accomplished in clinical practice. In the realm of medical diagnosis, Hick (1999) suggests that by exploring a patient's illness narrative, one can "re-establish the perceptual ambiguity of ordinary perception" as a "heuristic tool for discovering what has, by its ambiguous nature, so far escaped the medical grip" (p.136). By listening to a patient's narrative, a provider can perceive much more than what is limited by traditional clinical methods. This is especially pertinent for patients with endometriosis, who often present with varying and non-specific symptoms that make the condition difficult to diagnose. Moreover, Hick (1999) proposes that an open pattern of perception is needed to "follow the perceptual lines according to which a patient structures the reality of [her] illness," and thereby, understand the "*specific* sense a certain illness has for the individual patient" (p.136). Furthermore, a focus on the "open perception of lived experience" facilitates "mutual understanding, exchange and compromise" in the clinical encounter and establishes "a web of shared reality" between physician and patient (Hick, 1999, p.137). As symptoms like pain and heavy menstruation are so subjective, clinicians are only able to gain a true sense of each patient's experience of her symptoms by exploring the impact that they have on her life.

A question like, "where does it hurt?" simply requires a one-word answer. It limits an individual's ailment to one specific location, without realizing the way the illness permeates her life. By contrast, phenomenologically informed questions foster a space for subjectivity and creative adaptability, thereby acknowledging the context, experience, and relations of the ill person (Carel, 2019). One particular way that this can be accomplished is through the inclusion of phrases such as: 'How has this illness changed your life?' 'What aspects of it affect you the most?' 'How can those effects be made up for?' 'What are you stressed about?' and 'Can you tell me about the situations that make you anxious?' (Carel, 2019, p.108; Svenaeus, 2019, p.466). Such changes in verbiage can alter the patient-physician connection by emphasizing the patient's perception of her illness over the clinician's closed scientific perception of physical symptoms. By centering the patient's experience, functional assessments of pain in clinical diagnoses can transform into something more holistic.

Dr. Huang reflects on her own medical perception of Jane:

> The opportunity to simultaneously hear Jane's account and read her medical notes was a valuable learning experience but it also made me feel frustrated and ashamed. Why did it take so long for a doctor to recognize Jane's health problems as something other than premenstrual syndrome and the consequences of being a mother? At the same time, endometriosis is extremely difficult to diagnose, with symptoms often being non-specific and varying amongst individuals. Reading through Jane's medical entries, I cannot be certain that I would have made a different decision had I simply read her symptomatology of heavy periods and lower abdominal pain. The difference lies in adopting an open, ambiguous pattern of perception in addition to the scientific exploration of her symptoms. Perhaps if Jane's general practitioner had truly explored and listened to Jane's account of her lived experience, his understanding of the reality of her illness would have been much more congruous to her experience of it, and she would not have waited so long before receiving a diagnosis and support for her illness.

There have been a handful of studies on the medical experience of other patients with endometriosis. Patients often feel that their reports of pain are not believed or properly attended to. In a mixed methods study about the differing patient and physician perspectives in the clinical encounter, for example, researchers found that:

> Every patient talked about struggling with providers and feeling frustrated with the healthcare system. Patients noted that they encountered providers who lacked the skills and knowledge to properly manage the disease. Similarly, patients reported feeling patronized by providers during their respective endometriosis journeys. And whether it was before they received an official diagnosis or the years after, patients felt strongly that their concerns had not been heard. (Zale, 2020, p.72).

The disregard shown to patients with endometriosis is pervasive: in surveys and interviews, all of the patients highlighted their testimonies of pain being dismissed and devalued. These patients' testimonies reveal that not only is their perception of their illness different from that of their physicians, but so is their perception of the encounter itself.

Yet providers are at a disadvantage, given that they are not properly or thoroughly taught about endometriosis because it "is often considered a 'benign' female disease given that it is noncancerous and presents with diffuse symptoms in various parts of the body without a definitive cause" (Zale, 2020, p.71). The fact that providers, despite extensive training, are not given the tools to help their patients paints a grim picture for women's health. That there is a dearth of research on the topic, as well as meager training for obstetricians and gynecologists, points to deliberate disregard for both the development of knowledge about the condition and the health of patients suffering from it. Endometriosis thus remains invisible in contemporary medical culture because it is "largely ignored in government policy and research funding globally" (Hudson, 2022, p.21). While there are multiple factors that may contribute to this, it is undeniable that it is partly because there is not enough attention paid to women's pain in general.

The fact that female pain is not recognized in endometriosis is part of a larger history of shame and secrecy surrounding gynecological issues. According to philosopher Miranda Fricker (2011), when the response to testimony is poisoned by "prejudice" and a "deflated level of credibility to a speaker's word," there exists a kind of epistemic injustice, which she coins "testimonial injustice" (p.1). Instances of testimonial injustice are heightened when patients have marginalized identit(ies); women, for instance, often receive vastly different treatment of pain than do men. In "Coronary Artery Disease in Women: From the Yentl Syndrome to Contemporary Treatment," Vaina et al describes how women's pain is regarded as less serious than that of men. They explain that:

> Unlike men, women were submitted less frequently to any diagnostic or therapeutic intervention creating in this way dissimilarity on curing procedures. This alarming fact was described by Bernadine Healy, the first woman director of National Health Institute in United States, as the Yentl syndrome named after the Jewish heroine of Isaac Singer, who was masqueraded as a boy in order to be educated in the Talmud philosophy. Healy concluded that when a woman has been shown to have extensive CAD, like men, only then she gets the appropriate treatment. (Vaina et al., 2015, 12).

Yentl Syndrome demonstrates that women are seen as an "other," a deviation from the male norms of health. Women who do voice their pain face little chance of recognition. Pervasive gender stereotypes and a culture of patriarchal institutions lead to devaluation of women's own accounts of their pain. Yet this is only one amongst many examples of such medical care.

Dr. Huang's experience with Jane provides another example of how the medical system fails patients with endometriosis:

> Reflecting on Jane's experience, I found myself questioning why her doctor did not perform a pelvic examination when she presented with gynecological symptoms. If Jane had presented with a cough or shortness of breath, he would have listened to her chest. If she had presented with numbness and weakness, he would have performed a neurological examination. Why doesn't this rule apply to gynecological presentations? Female pelvic examinations are often associated with feelings of discomfort and shame, both by the doctors performing them as well as the patients receiving them, particularly if the doctors are male. There is an inherent structural belief that pelvic examinations must be justified, in a way that listening to a patient's chest with a stethoscope does not need to be.

In *Public Privates: Performing Gynecology from Both Ends of the Speculum*, Terri Kapsalis (1997) suggests that the inherent problem of the female pelvic exam lies in the fact that "it is a practice that necessitates the public exposure of the shameful privates" (p.5). She further characterizes the "shame associated with an exposed vulva, or the mere suggestion of displaying that very private part" as "excruciating" (Kapsalis, 1997, p.4). A roundtable meeting convened by the Society for Women's Health Research in 2019 determined that endometriosis-related stigma and its impact on psychosocial well-being are barriers that contribute to diagnostic delay (As-Sanie et al., 2019). Yet in the two decades since Kapsalis's writing, endometriosis-related stigma remains under-studied, with only a small handful of qualitative studies in medical literature (Sims et al., 2021). The shame observed by Kapsali is further compounded by patients' experiences of the trivialization and invalidation of their symptoms (Sims et al., 2021). In particular, the participants of one study reported that their experience of debilitating symptoms such as chronic pelvic pain, heavy bleeding and painful menstruation were "redefined and normalized" by others as their normal "load in life" (Seear, 2009, p.1223). Without efforts to elucidate and challenge these stigmas, individuals living with endometriosis will continue to be affected by their "negative effects on timely care, treatment and quality of life" (Sims et al., 2021, p.8). One way to challenge these stigmas is through a phenomenological approach, which fosters an open and non-judgmental discussion for women to disclose, reflect and discuss their lived-experience with endometriosis (Sims et al., 2021).

In order to challenge this stigma, one must also challenge widely-accepted practices and attitudes about who has the power to decide which parts of the body can be seen. How can we escape the inevitable imbalance of power between a subject (i.e. the patient) and her viewer (i.e. the clinician)? It is the clinician who decides whether a patient should have a pelvic examination. On top of this, women face an unfair expectation to perform as "ideal patients" who are "compliant, passive and accepting rather than active and questioning" (Kapsali, 1997, p.6). For Jane, and many other women with endometriosis, this expectation extends beyond the pelvic examination into their larger role as patients: Jane did not feel it was appropriate to correct her physician's misunderstanding of her lived experience or question his management of her condition. The imbalance in power and expectation for female performance contribute to the lack of mutual understanding between patient and physician, and subsequent delay in diagnosis and mismanagement of endometriosis. It is thus imperative that the medical world recognizes these stigmas and inequalities and empowers female patients and their physicians to challenge them.

A qualitative analysis of women's experience with their endometriosis diagnosis centers greatly on the importance of the physician's relationship with the patient. It has been shown that a "doctor patient alliance" is linked to better health outcomes (Fernley, 2021, p.40). When symptoms are dismissed, however:

> women with endometriosis have expressed the social stigma, shame and the social weight of being labeled a 'complainer' or a 'hysterical woman' and often seen as unable to cope or exaggerating when they have spoken up about their menstrual concerns. This stigma creates further barriers which can cause women to stay silent, especially because of cultural and social beliefs that a woman's menstrual suffering is an expected biological norm (Fernley, 2021, p.41).

Not only is their epistemic power stripped from them, but so is their trust in the medical system. This obstructs them from receiving adequate health care and positive health outcomes; thus, the difference in perspective in the clinical encounter can have far-reaching impacts both on the psychological identity of the patient and the trajectory of her treatment.

The pervasiveness of such experiences, in addition to the lack of attention paid to women's health on an institutional level in medical curricula, mean that misconceptions are perpetuated at the structural level. In "Structural Competency: Theorizing a New Medical Engagement with Stigma and Inequality," Helena Hansen and Jonathan Metzl (2014) argue that "stigmas are not primarily produced in individual encounters but are enacted there due to structural causes" (p.127). In other words, institutional misogyny must be met with institutional reform. They have proposed that medical education needs to incorporate what they have coined "structural competency." In order to address the structural issues within clinical care, structural competency includes training on how the power structures between physician and patient as well the interactions of physicians' own identities and structural backgrounds influence the clinical encounter. In practice, this includes fostering an open, ambiguous pattern of perception amongst physicians and acknowledging and validating women's pain.

Metzl and Hansen (2014) describe a structurally competent clinician as one who entertains "multiple interpretations for scenarios whose tensions are…too-often reduced to explanatory models" (p.131). This aligns with Hick's proposal for physicians to supplement scientific understanding with an open, ambiguous pattern of perception. Ultimately, this correlates with a phenomenological approach to understanding a patient's lived experience of illness, one that has been described and studied in writings by Havi Carel, S. Kay Toombs, and Richard M. Zaner. The same must be done for endometriosis, which has suffered from a lack of understanding from society and the healthcare system, an under-appreciation of female pain, and stigmatization of female genitalia. The broader structural implications of the lack of research and physician training reveal endometriosis as a glaring example of medicine's ignorance of patient embodiment and denial of women's pain.

But tides may be changing: Dr. Huang found that more and more, endometriosis patients' embodiment is being considered in the clinical encounter.

> Recently, while leading a group of medical students in a pediatric emergency department, I was pleasantly surprised to hear them consider endometriosis as a differential diagnosis for a 15-year-old female patient presenting with heavy and painful menstruation and lower pelvic pain. Rather than simply asking the patient about the nature of her symptoms, these students also explored their impact on her life, including her school attendance, engagement with her friends, and sexual activity.

Though significant work continues to be required on an individual and institutional level, this experience is a hopeful indication of progress towards structural competency and open perception in the medical world.

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