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Ina Hallström
Stockholm University
ina.hallstrom@gender.su.se

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Endo Episteme: Epistemic Injustice and the Misrecognition of Endometriosis

Ina Hallström

Abstract

The process of gaining recognition and treatment for a medical condition involves multiple stages where knowledge is negotiated along the way. This is particularly true for endometriosis, or “endo,” a chronic condition affecting one in ten menstruating individuals. In this article, I present a phenomenology of key epistemic practices involved in the journey toward knowledge about endo, based on interviews with fifteen individuals diagnosed with endometriosis in Sweden. These lived practices constitute what I call *endo episteme* and demonstrate how knowledge is gained, negotiated, or lost. Drawing on Miranda Fricker’s notion of epistemic injustice and Axel Honneth’s theory of recognition, I conceptualize the following practices: comparing-with, expressive uptake, a pedagogy of pain, the struggle for diagnosis, an epistemology of ignorance, and epistemic activism. Together, these practices shape the crucial processes of becoming a knower, becoming a patient, and becoming knowledge in relation to endo. This work contributes to feminist and social philosophy by enriching the frameworks provided by Fricker and Honneth, and it introduces novel concepts to deepen our understanding of the experiences of endo patients. The analysis of endo episteme emphasizes the central role of epistemic practices for the misrecognition of a gendered illness affecting millions worldwide.

Keywords: chronic illness, diagnosis, endometriosis, epistemic injustice, phenomenology, recognition

The process of gaining recognition and treatment for a medical condition involves multiple stages where knowledge is negotiated along the way. This is particularly true for endometriosis, a chronic condition that affects one in ten menstruating individuals worldwide. Endometriosis is characterized by the presence of endometrial-like tissue outside the uterus and is associated with chronic pain, infertility, and a negative impact on quality of life (Lökvist et al. 2016; Nnoaham et al. 2011). Symptoms are often normalized, and there is a well-described delay in diagnosis internationally. The gendered nature of the condition and the difficulties in receiving recognition, diagnosis, and treatment (Ballard, Lowton, and Wright 2006;

Seear 2009, 2014; Hudson 2022; Whelan 2007) make endometriosis a pressing feminist issue.

In this article, I explore how individuals with endometriosis progress from experiencing pain to knowing that they have this specific condition. I analyze how knowledge about endometriosis, or “endo,”¹ appears and takes on meaning in the lifeworld, using in-depth interviews with fifteen individuals who have been diagnosed with the condition.² The interviews are part of a larger project on the recognition of endometriosis in Sweden (see Hallström 2024). Despite Sweden being declared the best country in the world for women, the diagnostic delay was five to seven years in 2018 (SBU 2018). During my analysis of the interviews, knowledge emerged as a central theme in how endo was experienced and recognized. Even so, research on the connection between endo and knowledge is limited. A notable exception is Emma Whelan’s (2003, 2007, 2009) work, which uses the concept of “epistemic communities” to examine systems of pain documentation, endo-patient communities, and gynecological literature, respectively.³ Another example is Nicky Hudson’s (2022) description of endo as characterized by an “epistemology of ignorance.” Studies also indicate difficulties in making sense of and communicating endo pain and getting others to understand the patient’s situation (Bullo 2020, 2021; Bullo and Hearn 2021; Whelan 2007; Helosvuori and Oikkonen 2023).

But the everyday epistemic practices involved in the diagnostic journey have not been made a central concern, nor has their relation to processes of recognition. Through this article, I intend to address both issues. Using endo as a case from “messy empirical reality” (Zala et al. 2020) can provide valuable contributions to current theories of epistemic practices and recognition. Taking a bottom-up approach, starting from particular real-world issues, and engaging in “real-world political philosophy” (Wolff 2015, 22) can inform both normative theorizing and policy, offering insights on “what should be done here and now” (Zala et al. 2020, 37). Understanding the epistemic obstacles of the diagnostic journey from a patient perspective can shed light on the reasons behind delays in diagnosis and treatment, ultimately leading to improved quality of life for patients. This is particularly

¹ My use of the emic term *endo* is part of an endeavor to treat the condition as a phenomenon as it appears in the lifeworld of interviewees.

² I have conducted in-depth semistructured interviews with fifteen individuals diagnosed with endo, ranging from eighteen to sixty-two years old at the time of the interview in 2018 and coming from different parts of Sweden. The interviews have been digitally recorded and transcribed verbatim. Informed consent has been obtained, as well as ethical clearance of the project as a whole.

³ See also Lindgren and Richardson (2023) and Melander (2019, 2021).

important as individuals who are ill may be especially susceptible to epistemic injustice (Carel and Kidd 2014).

Specifically, I provide a phenomenology of the “lived” (*erlebt*) epistemic practices involved in the journey toward knowledge about endo. These practices constitute what I call “endo episteme.”⁴ Using a theoretical framework that combines Miranda Fricker’s (2007) notion of epistemic injustice with Axel Honneth’s theory of recognition, the article seeks to answer the following questions: How do interviewees come to know endo? How is knowledge gained, negotiated, or lost? What are the implications for interviewees’ relations to self? Through the analysis of endo episteme, I identify and conceptualize a number of epistemic practices in the lifeworld of interviewees: comparing-with, expressive uptake, a pedagogy of pain, the struggle for diagnosis, an epistemology of ignorance, and epistemic activism. These practices shape the crucial epistemic processes of *becoming a knower*, *becoming a patient*, and *becoming knowledge* in relation to endo

I will begin by explaining how I use the notion of “epistemic recognition,” drawing on Fricker’s and Honneth’s theories. Then, I present the phenomenology of endo episteme as it appears in the lifeworld of interviewees. Finally, I discuss the epistemic practices identified and how they contribute to the acquisition, negotiation, and loss of knowledge. I conclude by suggesting ways to overcome epistemic obstacles, stressing the importance of receiving epistemic support from others, expanding and disseminating medical knowledge, and transforming social norms and biases regarding menstruation and pain.

From Epistemic Injustice to Epistemic Recognition

The relation between knowledge and the identity or social location of the knower has been well explored within the fields broadly labeled feminist epistemology and critical social epistemology. This has meant scrutinizing how reason has been perceived as male in the history of Western philosophy (Lloyd 1996), how knowledge has been seen as objective even when it is partial, how the knower has been perceived as a disembodied “conquering gaze from nowhere” (Haraway 1988, 581), and how the tradition of epistemology itself has been based on artificial

⁴ I use the term “episteme” to capture and analyze epistemic practices related to endo within the lifeworld of interviewees. Inspired by Foucault, I use the concept broadly to include the historical conditions that make knowledge possible, “whether expressed in a theory or silently invested in a practice” (Foucault 2001, 183). Foucault’s use of episteme has been compared to Thomas Kuhn’s idea of a paradigm, but it extends beyond science. In his later work, Foucault emphasizes that multiple epistemes can coexist as part of different power-knowledge systems (Foucault 1980).

exclusion of views due to nonepistemic reasons such as racism or sexism (Alcoff 2008, 714).

In recent years, Miranda Fricker has sparked renewed discussion by addressing the “epistemic injustice” involved in everyday epistemic practices—that is, “those human practices through which knowledge is gained, or indeed lost” (Fricker 2007, vii). Although Fricker coined the term, some argue that thinkers such as Anna Julia Cooper and Gayatri Chakravorty Spivak already anticipated the idea, and many others have since delved into the recognition of knowers (May 2014; Spivak 1988; Collins 1990; Alcoff 1991, 2000; Lorde 2007; McKinnon 2016). Of particular interest for the present discussion, Fricker’s concept of epistemic injustice has been put in conversation with the recognition theory of Axel Honneth in a 2018 special issue of *Feminist Philosophy Quarterly* titled “Epistemic Injustice and Recognition Theory.” Combining recognition theory with epistemic injustice offers a useful framework for understanding the impact of epistemic practices on both knowledge production and the individual’s self-relation. Recognizing someone as a “knower” involves acknowledging their status and regard, allowing for a positive self-relation based on their rightful inclusion in socioepistemic practices (Congdon 2018, 4–6). Conversely, epistemic injustice can rob individuals of their status as rational inquirers and lead to self-alienation (Giladi 2018). By examining endo episteme through the lens of recognition, we can analyze how recognition is manifested in everyday epistemic practices and its impact on both knowledge and the knower.

Honneth’s philosophy of recognition, as outlined in *The Struggle for Recognition* (Honneth 1995), is based on the idea that mutual recognition is essential for human flourishing. A central premise is that individualization and recognition are fundamentally intertwined and that social change is driven by the continual expansion of relations of mutual recognition. Honneth identifies three main modes of recognition: love or emotional support, respect, and esteem. These modes help us develop and sustain corresponding positive self-relations. We develop basic “self-confidence” by being loved and cared for, we develop moral “self-respect” by being awarded the same rights as anyone else, and we develop “self-esteem” by having our unique abilities and contributions valued by others.

Epistemic injustice, as defined by Fricker (2007, 1), is “a wrong done to someone specifically in their capacity as a knower.” Fricker identifies two types of epistemic injustice: testimonial injustice and hermeneutical injustice. “Testimonial injustice” happens when a hearer attributes less credibility to a speaker’s word due to prejudice or stereotypes. “Hermeneutical injustice” occurs when a gap in the shared social imaginary puts someone at an unfair disadvantage in trying to make sense of their own social experience. This gap can lead to “hermeneutical marginalization,” making it difficult for people to make sense of and articulate their experiences in a satisfactory way. The two types of injustice have different objects in

focus. Testimonial injustice relates to the identity of the knower and how it affects perceived credibility, while hermeneutical injustice relates to the types of experiences available in shared hermeneutical resources.

In the special issue's afterword, Fricker uses Honneth's theory to propose a tripart notion of "epistemic recognition" that forms the basis for epistemic self-confidence, self-respect, and self-esteem (Fricker 2018, 2). I will refer to the corresponding modes of recognition as epistemic support, respect, and esteem. "Epistemic support" concerns emotional needs and support within the sphere of primary relationships of love and friendship. "Epistemic respect" relates to our rights and our status as legal and moral equals. "Epistemic esteem" concerns the status of our ways of life and our contributions to shared hermeneutical resources. This tripart notion provides a useful framework for analyzing endo episteme and can help identify instances where sufficient epistemic recognition is lacking. Furthermore, it suggests potential remedies, as the three modes of epistemic recognition should be viewed as ways to overcome epistemic injustices within each sphere.

In addition to the three modes of epistemic recognition, I utilize Honneth's (2003, 114) idea of recognition theory as a phenomenology of social experiences of injustice. Similarly, my approach can be characterized as a phenomenology of experiences of epistemic injustice, based on the narrated experience of interviewees. Phenomenology aims to describe the meaning and structure of phenomena we experience in everyday life. It challenges the notion that subject and object can be neatly separated and instead focuses on how the meaning of phenomena is constituted by and bound up with human activity. Lifeworld perspectives on illness are particularly important given that medical knowledge has historically ignored and devalued patient experience, or "the voice of the lifeworld," along with social and cultural dimensions of health and illness (Whelan 2009). By using phenomenology, we can "move from the singularity of the first-person narrative to an account that seeks to identify, describe, and analyze generalities and typical features of the experience as such, while examining how this experience resides within and intersects with the broader lifeworld" (Fisher 2014, 28).

Drawing on the narrated experience of interviewees, I identify, describe, and analyze typical features of endo episteme. The three modes of epistemic recognition—epistemic support, respect, and esteem—serve as analytical categories that structure the analysis. In relation to each mode, I identify a central epistemic process: *becoming a knower*, *becoming a patient*, and *becoming knowledge*. In relation to each process, I conceptualize typical epistemic practices. I understand these as practices of epistemic recognition through which knowledge of endo is gained, negotiated, or lost.

Becoming a Knower: An Expression of Epistemic Support

To understand what it means to become a knower in relation to endo, we can begin with the concept of “epistemic support.” Epistemic support is related to our individual needs within the sphere of primary relationships of love and friendship. In Honneth’s (1995) vocabulary, emotional support affirms someone as deserving and worthy of others’ caring attention. It enables us to develop self-confidence by having our individual needs and emotions nurtured and taken care of. Epistemic support is related to what Fricker calls epistemic self-confidence, which concerns the most profound level of a person’s sense of epistemic selfhood, risking the deepest possible effects on a person’s epistemic agency (Fricker 2018, 3). I identify two prominent epistemic practices that appear to be essential for becoming a knower. The first is *comparing-with*, which involves comparing our own experiences to those of others in order to gain a deeper understanding of these experiences. The second is *expressive uptake*, which involves receiving uptake that enables us to express and make sense of experience. These two practices are important sources of epistemic support that enable epistemic agency and make it easier to become a knower in relation to endo symptoms.

I will start with comparing-with and the interviewees’ efforts to first make sense of endo symptoms. When I ask interviewees about their first experiences of symptoms, they often describe a situation characterized by *not knowing*. For instance, one interviewee describes the experience of the first symptoms—a “pretty severe pain” at the age of 10—as characterized by a lack of knowledge:

I started experiencing symptoms already as a child. I had my first period at 10 years old, and shortly after that I started having pain. Pretty severe pain. But when you were that young you didn’t understand . . . You know, I barely knew at that age what menstruation was. That is, when I was 10.

The pain described in the excerpt is retrospectively attributed to, or known to be, endo; but at the time, the interviewee did not understand the nature of the pain, and she barely knew what menstruation was. Although the period of unknowing varies in length among interviewees—from months to several years—most have similar experiences of a pain they fail to classify.

In many cases, our knowledge of illness follows a similar path: an unpleasant experience gets classified as the symptom of an illness once diagnosis is established. The term “diagnosis” originally means distinguish or discern (from *dia* “apart” and

gignōskein “to know”),⁵ and it is through the category of diagnosis we tell one condition apart from another. Here, I focus on the process preceding diagnosis, sometimes referred to as “phase 0” of the diagnostic journey (Geng, Sum-Ping, and Geng 2019). As many interviewees are young when symptoms first appear, they usually begin this journey by discussing symptoms with a parent, sibling, or friend before seeking medical care. These early investigations follow the pattern I call comparing-with and involve how individuals make sense of their experience by comparing it with others.

Phenomenology and recognition theory understand human existence as fundamentally characterized by intersubjectivity and coexistence with others. Martin Heidegger introduced the concept of being-with (*Mitsein*) to describe this human quality of always already being with others of its kind. For Heidegger, our understanding of our own existence involves the understanding of others (Heidegger [1927] 2010, 161). The practice of comparing-with is an aspect of our being-with, and it captures how interviewees come to understand their own experience *with* others by way of comparison. By comparing-with, people learn to identify a phenomenon or an experience as something specific, such as the symptom of an illness, or simply as something different from others’ experience. Through the practice of comparing-with, interviewees find answers to questions like: What is this? Do others experience what I do? Is this normal?

Comparing-with is a relational form of understanding—an epistemic practice that occurs throughout life and in relation to both concrete and “generalized others” (Mead 1934). However, the focus here is comparisons within the immediate social network, which tends to be smaller during childhood and dominated by the immediate family (Wrzus et al. 2013). I understand comparing-with as a practice that relies on family and friends to indirectly offer epistemic support by sharing their experiences. In doing so, they provide a crucial hermeneutical resource for the interviewees. When interviewees state that they “barely knew at that age what menstruation was,” it often means that they had no conception of menstruation because it was not discussed by people in their surroundings. Similarly, many interviewees describe that they had never heard of the concept of endometriosis when growing up and only realized that something was wrong because none of their friends “had it *like this*.”

During an interview, I met a mother and daughter who were both diagnosed with endometriosis but had different experiences of comparing-with:

⁵ *Merriam-Webster*, s.v. “diagnosis (*n.*),” accessed November 18, 2024, http://www.merriam-webster.com/dictionary/diagnosis_

Mother: When I grew up and had all these problems, there was no internet or anything like that. [. . .] So, I had no idea that other people did not experience what I did.

Daughter: But mom, it wasn't the internet that helped me see things differently, it was when I started speaking to others about it.

Mother: But I *didn't* speak others about it. [. . .]

Daughter: It was when I started speaking to others and saying like: "You know when this happens?" and they were like: "No."

Mother: But I *never* spoke to others about it.

The passage illustrates how the mother lacked opportunities for comparing-with in relation to endo. She did not have dialogue with others or access to online resources. She had no forum where she could gain knowledge related to symptoms and was not diagnosed until years later, as an adult. This lack of dialogue is reflective of the menstrual stigma prevalent in society, which has been identified as a common cause of self-silencing (Johnston-Robledo and Chrisler 2013; Seear 2009; Montgomery 1974). Other interviewees also express similar sentiments, stating that "People just didn't talk about issues *like that*." When an area of experience is considered taboo due to stigma, it can inhibit the practice of comparing-with. Self-silencing also occurs when severe menstrual pain is perceived as inherently normal (see Armour et al. 2021). Several interviewees express this sentiment, saying, "I didn't talk to anyone because I thought everyone had it like me. [. . .] I never thought it was abnormal." Prior research has also highlighted the importance of comparison for knowledge about endo. This applies to both an individual's past personal experiences and the experience of others. Elaine Denny (2009, 988–89) finds that

women who had always had painful periods were more likely to perceive this as normal, because they had no other experience for comparison, and for these women either their pain became so severe that they eventually sought medical help or comparison with other women provided the realization that they were different.

In contrast, for the daughter, it was through dialogues with friends that she realized that everyone did *not* experience what she did. She also had access to other sources of knowledge. Eventually, she turned to online sources, and later she gained access to medical journals when becoming a university student and dived into those resources as well. The differences between mother and daughter demonstrate that the act of comparing-with does not take place in a vacuum. Access to knowledge is related to the hermeneutical resources available in society. These resources vary over

time and place, leading to intergenerational differences. Individuals who lack opportunities for comparing-with are disadvantaged in making sense of their experience, which can make it more challenging to take the next step and seek health care. However, despite the different opportunities for comparing-with and different trajectories to becoming knowers, the mother and daughter share some important similarities, which will be discussed next.

The second epistemic practice, expressive uptake, involves recognizing testimonies of endo pain. Sue Campbell (1997) argues that feelings are socially shaped, sanctioned, and stabilized. For Campbell, feelings are formed through acts of expression that we use to communicate affective significance. We rely on others for expressive uptake so that feelings can be individuated and successfully communicated. However, our feelings can also be subjected to suppression, distortion, and manipulation (Campbell 1997, 3–4). As Campbell notes, “If what we feel is, by and large, what we express, then people can control our feelings by controlling our modes of expression” (Campbell 1997, 135). Because of this public dimension of feelings, our affective lives can be sites of oppression. For instance, attempts to communicate affective significance can be undermined by characterizing the emoter as bitter, sentimental, or overly emotional. According to Campbell (1997, 166–67), such strategies of “interpretive dismissal” are often directed at women and have the power to “to limit our ways of acting in the world, and, consequently, our effects on the world.” Campbell’s account is valuable because it adds a political dimension to the analysis of feeling and sheds light on a form of everyday hostility or “discursive abuse” (Giladi 2018) that, according to Campbell, is commonly directed toward gendered and racial others. I suggest that we understand expressive uptake of testimonies as a crucial part of the epistemic support needed to become knowers and develop epistemic self-confidence.

For instance, the daughter describes how her father treated both her and her mother as “whiny” when they talked about their symptoms or how they felt, and she says that the rest of the family did not seem to care. In Campbell’s (1997, 165) vocabulary, this experience can be described as being “emotionally manipulated through the unsympathetic or hostile interpretive practices of others.” Moreover, the daughter explicitly describes the father’s dismissive behavior as a way of undermining their self-confidence and sense of truth: “I am 90% sure that this was a way for him to undermine our confidence in ourselves and in what we know is true.” I interpret the statement as referring to a pattern of repeated dismissal; their sense of truth would not be undermined if such dismissal was a one-time event.

The daughter’s statement demonstrates the importance of uptake from others for the process of becoming a knower. It also illustrates how recognition, sense of truth, and self-relation can be intertwined. In order to become a knower, you must be recognized as a knower with valuable knowledge to offer to others. The

interviewees also describe the gendered nature of endo as a probable reason why fathers are often unable to understand, listen, or care. In contrast, mothers are mostly seen as sources of support and comparing-with. This could be due to the listener's personal familiarity with the topic. However, menstrual stigma reasonably plays a role, and the gender of the speaker also seems to matter. One example of this is an interviewee who describes that her father only started to listen when her boyfriend spoke to him about her illness.

Arguably, the role of gender can contribute to both testimonial and hermeneutical injustice in the context of endo pain. Hermeneutical injustice can shape how the experiences are perceived, while testimonial injustice can impact whose testimony is heard and believed. Since pain is an inherently subjective experience that is known by being felt, misrecognition of pain amounts to something more than a dismissal of a mere fact: it undermines the knower of pain—specifically in their capacity as knowers (Fricker 2007). Conversely, awarding the speaker with attention, encouragement, and patience—what Matthew Congdon (2018, 12–13) calls “epistemic love”—is analogous to providing expressive uptake of testimonies. Without epistemic love, a person's sense of truth can be undermined, making it more challenging to become a knower, even regarding their own feelings and experiences. Dismissive responses can disrupt and delay the process of becoming a knower given that an individual who is unable to individuate and express their experience is less well-equipped to take the next step and seek health care.

Taken together, the experiences of interviewees indicate that becoming a knower in relation to endo pain is a highly relational process. Others are needed in two key senses, for comparing-with and for expressive uptake. Comparing-with helps individuals to make sense of their experience, to identify it with or discriminate it from others' experience. Menstrual etiquette and stigma shape what people feel comfortable talking about and what kind of knowledge is available in shared hermeneutical resources. Comparing-with concerns hermeneutical injustice because when it is lacking it involves unmet needs of understanding (Fricker 2007). The practice of expressive uptake is connected to testimonial injustice as it involves the improper uptake of testimonies. However, since expressive uptake enables individuals to form and express the affective significance of experience, it also has hermeneutical dimensions. Proper uptake constitutes the kind of epistemic love and support important for epistemic agency and confidence. Without opportunities for comparing-with and expressive uptake, individuals may be more reluctant to take the next step toward becoming a patient.

Becoming a Patient: An Expression of Epistemic Respect

To understand what is at stake in the process of becoming a patient, I now turn to “epistemic respect,” which concerns our status as legal and moral equals.

According to Honneth, we develop self-respect by being awarded the same basic rights as everyone else. Similarly, Congdon regards epistemic self-respect as based on the egalitarian notion that there is a basic form of respect owed to any knower, irrespective of who they are (Congdon 2018, 13). Correspondingly, denial of rights or ostracism can lead to a loss of epistemic self-respect based on “the feeling of not enjoying the status of a full-fledged partner to interaction, equally endowed with moral rights” (Honneth 1995, 133; quoted in Fricker 2018, 2). Here, I primarily associate epistemic respect with the medical sphere and the egalitarian right to health.

According to the constitution of the World Health Organization (1946), “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.” But the experience of interviewees suggests that gender bias regarding pain undermines the egalitarian right to health. When someone is ill, their right to health depends on becoming a patient through the classification of diagnosis—in this case, an endometriosis patient. If someone is ill but not recognized as a patient, their right to health is compromised. There are two key epistemic practices that shape the process of becoming a patient. The first is *the pedagogy of pain*, which refers to the common belief that menstrual pain is normal. The second is *the struggle for diagnosis*, which describes the practice of interviewees seeking recognition as patients with medical rights. Both practices describe the challenges involved in becoming patients and being granted the egalitarian right to health.

The pedagogy of pain can be illustrated by an interviewee’s first encounter with a doctor about her menstrual pain at the age of thirteen. It was a female doctor who responded by saying that pain was something she had to get used to:

This is the way it is, and you’ll have to get used to it; this is the way it will always be. I have really painful cramps too. You’ll have to endure. I climb the walls at times from pain. [. . .] There is nothing to be done.

Although it may be uncommon for doctors to share personal experience in this way, many interviewees describe both male and female doctors urging them to accept the fact that “menstruation does hurt”—“it’s just the way it is”—and that it is up to them to learn to endure. The same kind of message is so common in the interviews that it resembles a mantra, repeated again and again, teaching young people with endo how they are supposed to react to their pain. I refer to this mantra as “the pedagogy of pain,” which perpetuates variations of the theme that menstruation hurts and that womanhood is inherently painful. The mantra is most often associated with doctors in the interviews but occurs both within and outside the medical sphere. The

interviewee states that it was especially difficult to reach out to others because adults around her, both doctors and others, would tell her that the pain was normal: “It’s difficult when you’re a kid and get these responses. It’s hard to keep on insisting when all the adults tell you that this is the way it is.” Doctors and other adults are usually attributed epistemic authority over children due to their education, institutional position, and age. Becoming a patient can be especially difficult when normalization and dismissal of endo pain, widely reported as a likely contributor to diagnostic delay (Seear 2009), comes from such authorities.

In addition to menstrual cramps, a similar pedagogy of pain seems to affect the perception of other kinds of pelvic pain. For some interviewees, pain occurs during penetrating sex (*dyspareunia*), and the idea that pain is a normal part of being a woman is also mentioned in their descriptions: “It’s the same there. I have thought that ‘Sex is painful; it’s like that for everyone.’” Several interviewees find gynecological examinations painful and recall gynecologists not being careful despite clearly causing pain. One interviewee describes intrauterine device (IUD) insertion to be so unbearable that she eventually had to be sedated to go through the procedure. Another interviewee states that the responses she received over the years led her to form a notion of pain as practically inevitable for women. In contrast, one interviewee recounts a recent positive experience where a gynecologist said, “Let me know if anything hurts”—which surprised her because this had never happened before. Her expressions of pain were usually ignored.

These experiences all demonstrate a cultural association between pain and female gender. Prior research has shown that women are more likely to seek treatment for pain, but they are also more likely to be inadequately treated for their pain. This undertreatment has been linked to gender bias regarding women’s pain experiences (Hoffmann and Tarzian 2001; Zhang et al. 2021; Samulowitz et al. 2018; Hoffmann, Fillingim, and Veasley 2022). Women are also more likely than men to have their pain attributed to psychogenesis (Hoffmann and Tarzian 2001).

Several interviewees describe being treated as “hysterics” or “hypochondriacs” by doctors. The mother already mentioned says: “It’s mental according to them. It’s always mental. And some doctors are *not* happy when you think for yourself.” The figure of the hysteric is so pervasive in relation to endo that Cara E. Jones (2015, 1084) has suggested that endo has taken up a diagnostic and cultural location once occupied by hysteria: “Each disease pathologizes not only certain physical symptoms, but also social and cultural deviations from female gender norms.” Similarly, Elaine Showalter (1987) has demonstrated how cultural norms of proper feminine behavior has historically shaped the definition of mental illness. I see the pedagogy of pain as a manifestation in the lifeworld of gender bias and historical norms surrounding pain. By its repetitive structure, over time and across spheres, the pedagogy of pain can be understood as performative in that it puts forward an ideal

subjectivity related to pain: a person who ignores and endures. A failure to perform according to the pedagogy of pain exposes a person to a cultural arsenal of credibility downgrading, and the figure of the hysteric operates as a personification of unwanted behavior that still looms large over endo patients.

The association between pain and womanhood has gained renewed critical attention in recent years. Within both academic and lay contexts, gender inequality in pain is being conceptualized as a “gender *pain* gap,” alluding to the so-called gender pay gap (Pase 2021; Bimpong et al. 2022). Painful or abusive examinations are increasingly being addressed in social media, news, and research as part of the broader phenomena of “gynecological violence” and “obstetrical violence”—forms of violence that have long remained hidden from public scrutiny (Simonovic 2019; Diaz-Tello 2016). The term “medical gaslighting” is being used in media and research to draw attention to experiences of dismissal and misdiagnosis, both regarding endo and other illnesses (Sweet 2019; Vargas 2022). This can be read as responses to the pedagogy of pain on a collective level. On the individual level, a main alternative to being seen as hysteric or accepting the ignore-and-endure-position is to pursue another form of subjectivity, the subjectivity that has the power to claim rights within the medical sphere. You have to become a patient.

The second epistemic practice, the struggle for diagnosis, refers to the efforts and strategies used by interviewees to become recognized as patients. Diagnosis is a crucial step in becoming a patient, a person with medical rights and needs. Doctors have long been considered sources of truth on medical matters. The term “doctor,” indicating a learned person, comes from the Latin word *docere*, which means “to teach.”⁶ However, the interviewees’ experiences show that the clinical encounter is not just about expertise but is also a site of struggle. Alexis Shotwell aptly describes the medical classification of diagnosis as “a political formation with material effects” (Shotwell 2014, 509). Many interviewees describe their initial interactions with doctors as characterized by dismissal or disbelief. They were often repeatedly sent home with over-the-counter painkillers or hormones, without further referrals, examination, or diagnosis. While Fredrik Svenaeus (2000) characterizes the clinical encounter as “an interpretive meeting,” Jonathan Banks and Lindsay Prior (2001, 12) go a step further by describing it as a “site of a micro-political struggle” between patient and doctor to define the nature of the patient’s disease. It is in this light I understand the struggle for diagnosis—it is a struggle over interpretation and classification of patients’ experiences, with high stakes for the patient in terms of recognition, diagnosis, and treatment.

⁶ *Merriam-Webster*, s.v. “doctor (n.),” accessed November 18, 2024, <https://www.merriam-webster.com/dictionary/doctor>.

In many cases, interviewees learn about their diagnosis themselves, often through Google searches, the media, or friends. Doctors in these situations are needed to confirm the diagnosis rather than discover it. But when they go to the doctor to get their diagnosis confirmed, some doctors refuse to conduct the necessary investigation, and interviewees struggle to get referrals, sometimes for years. To overcome this, they use strategies such as seeking a new doctor or an especially good doctor, often by recommendation from other endo patients. One interviewee, for example, found the diagnosis online and brought the findings to a doctor, saying, “I would like to be investigated for endometriosis because I suspect that this is what I have.” The interviewee recounts that the doctor was “very skeptical” and suggested that even if it was endo, the treatment would still be the same—hormones—and there was no need “to have it on paper.” It was only years later, after coming across a nurse who had extensive experience with endo, that she was referred to a specialist. The specialist identified endometrial tissue attached to her uterus, ovaries, and abdomen. By the time she had the surgery, it had been eleven years since she first experienced symptoms, and she had struggled to be taken seriously by medical professionals.

Receiving a diagnosis often constitutes a critical turning point for interviewees, clearly marking a before and after in their lives (see Whelan 2007). Interviewees often express that getting a diagnosis validates that they are not “insane” and that their symptoms are not “all in their head”:

It was a relief just to know I wasn’t imagining things because that’s how it felt, like I had imagined everything and that I am somehow weaker than other women who can manage their menstruation.

The statement illustrates the positive impact that a diagnosis can have on a person’s self-relation and even their sense of sanity. Another interviewee describes receiving a diagnosis as a “victory” because she had been certain of the diagnosis all along. Prior studies have also shown that identifying a condition through diagnosis is significant on several levels, including the individual, collective, and societal levels (Brown, Lyson, and Jenkins 2011; Hudson 2022).

When interviewees experiencing severe symptoms are not recognized as patients, it often takes a toll on their self-relation. This aligns with Honneth’s theory of recognition, as interviewees report that they started questioning themselves and their sanity due to how medical professionals treated them. Such experiences can damage their epistemic self-respect, as they are not considered “a full-fledged partner to interaction” (Honneth 1995, 133; quoted in Fricker 2018, 2). Several interviewees associate this loss of credibility with gender. One interviewee recalls

starting to think that there was something wrong with the way she behaved that made doctors not listen to her. She believed that she “gave off a fragile impression” or that her being “beautiful” and “looking healthy, with rosy cheeks” might have been a disadvantage for her. She recalls an ultrasound where the doctor said that she was unlikely to have endo because she had a “fantastic-looking uterus” and a body “made for having kids.” These associations with femininity, beauty, and fertility were somehow connected with a lower probability of having endo. Looking good was associated with feeling good, in line with what has been described as the “beautiful is healthy” stereotype (LaChapelle et al. 2014). According to another interviewee, “I am treated this way because I am a woman.” Interviewees highlight female gender and youth as particularly associated with not being listened to or taken seriously.

Repeated negative experiences of this kind led several interviewees to adopt different coping strategies. For example, one interviewee started bringing a friend to doctor’s appointments because she had developed what she refers to as “doctor anxiety,” a version of *iatrophobia* (fear of doctors). Another interviewee took “a pause from doctors” for several years and refrained from seeking medical attention because of the bad treatment she experienced. Others discuss potential tactics, such as bringing a man to the doctor’s office, perhaps a father or a friend, based on the belief that men are more likely to be heard. These tactics can be seen as responses to the pedagogy of pain that are mobilized as part of the struggle for diagnosis.

While diagnosis often marks a significant turning point, it does not always solve the struggle altogether. For example, during a visit to the emergency room, a doctor suggested to one interviewee that her pain could be related to her history of posttraumatic stress disorder (PTSD) and asked if she had attempted electroconvulsive therapy (ECT). The interviewee describes how the situation made her feel: “Once again, they were calling me hypochondriac. That made me infuriated. How could I be a hypochondriac when you yourself opened me up on the operating table and gave me this diagnosis and then treated me like this afterward?” The statement may seem extreme, but prior research shows that some endo patients experience disbelief and delegitimization of their symptoms before, during, and following diagnosis (Hudson 2022).

Taken together, the pedagogy of pain and the struggle for diagnosis offer stark contrasts to the egalitarian principle that everyone has the same right to health. The experiences of interviewees are, in many cases, the opposite of being considered “a full-fledged partner to interaction” (Honneth 1995, 133; quoted in Fricker 2018, 2), which constitutes a basis for epistemic self-respect. Being labeled a “hysteric” or “hypochondriac” constitutes obstacles that interviewees have to overcome in order to become proper patients. Such labels are examples of credibility downgrading, which Fricker regards as typical of testimonial injustice. Consequently, it is through

the struggle for diagnosis, patienthood, and proper treatment that a sense of epistemic self-respect can be maintained.

Becoming Knowledge: An Expression of Epistemic Esteem

I finally turn to the concept of “epistemic esteem,” which is closely tied to the process I call becoming knowledge. Epistemic esteem concerns social esteem in relation to knowledge. More specifically, the process of becoming knowledge concerns the status of endo experience in shared hermeneutical resources—that is, whether the illness and lived reality of interviewees is taken up as knowledge within society as a whole. Has this kind of experience succeeded in becoming knowledge? For Honneth, self-esteem is developed through the experience of having one’s contributions, abilities, or way of life valued by society. For Fricker (2018, 3), people can be “hermeneutically marginalized” with respect to regions of experience due to a lack of shared concepts, meanings, and interpretative tropes to make sense of their lived reality. Even though shared with an in-group, such experiences cannot be rendered fully intelligible across social space because of a structural “under-contribution” to shared hermeneutical resources. If someone’s “pattern of self-realization is unfairly met with disapproving or even disgusted bewilderment” this can cause a loss of epistemic self-esteem (Fricker 2018, 3). I identify two main epistemic practices that are crucial for becoming knowledge. The first is *the epistemology of ignorance*, which refers to a general lack of knowledge related to endometriosis. The second is *epistemic activism*, which concerns interviewees’ responses and attempts to change this circumstance.

Encountering an epistemology of ignorance can be illustrated through a few examples. I have already described the experience of *not knowing*, which often accompanies early symptoms of endo. I have also mentioned how interviewees have difficulties distinguishing ordinary menstrual cramps from the symptoms of illness. Prior research indicates that women face difficulties in understanding what constitutes “normal” menstrual pain or bleeding due to the cultural expectations of silence and concealment called “menstrual etiquette” (Hawkey et al. 2022; Laws 1990; Seear 2009). This menstrual etiquette has been found to contribute to poor knowledge of one’s own anatomy and poor health literacy, which is associated with overall worse health status (Armour et al. 2021; Hawkey et al. 2022).

Additionally, interviewees also express an awareness of the fact that different kinds of diagnoses have different statuses. In addition to endo, the mother and daughter interviewees both have irritable bowel syndrome (IBS) and other health issues also considered low status:

We have so many weird problems, and who knows? It could be related to endometriosis—it could be something else. I think that there are

certain things that doctors just ignore. In twenty years, there will be a diagnosis. Just like with diabetes, there was *another kind* of diabetes that appeared later in life. I am totally convinced that once they pull their finger out and start doing the research, they will figure out a thing or two! They checked me for fibromyalgia, but I don't have these tender points, so they gave me another trashcan diagnosis: myofascial pain syndrome. I think they have given me every damn trashcan diagnosis there is.

In the statement, the mother describes their symptoms as being “weird,” which I interpret as experiencing symptoms that are on the outskirts of medical knowledge. She also describes that doctors tend to ignore these kinds of symptoms, but she believes that medical knowledge will probably catch up eventually and the status of such symptoms will change, “just like with diabetes.” A “trashcan diagnosis” is described as something doctors “give” away, almost to get rid of the problem, when they cannot classify the condition with a proper diagnosis. The notion of endo as a “women’s disease” and the associations with hysteria or trashcan diagnoses shape the recognition experience and the hermeneutical marginalization of endo. Low status and poor knowledge appear as interconnected characteristics of endo episteme.

How can we make sense of the status and lack of knowledge that affects interviewees’ endo experiences? Menstrual stigma and menstrual etiquette make it easier to understand the lack of knowledge on an individual level, but what about the collective level of medical knowledge? One way of making sense of the lack of knowledge on the collective level is to understand it as the result of epistemic practices that produce ignorance. In a special issue of *Hypatia* on “Feminist Epistemologies of Ignorance,” Nancy Tuana and Shannon Sullivan (2006) argue that in order to fully understand knowledge production, we must also understand the practices behind *not knowing*. Linda Martín Alcoff (2007, 39) similarly argues that we should understand ignorance “not as a feature of *neglectful* epistemic practice but as a *substantive* epistemic practice in itself.” In their discussion of the production of ignorance, Fricker and Jenkins describe “the epistemic system” (Fricker and Jenkins 2017, 270) as a process linking together testimonial and hermeneutical injustice:

- (1) Socially patterned testimonial injustice tends to produce (2) hermeneutical marginalization in relation to one or more areas of social experience; which in turn tends to produce (3) hermeneutical injustice in relation to the intelligibility of those areas of experience. (Fricker and Jenkins 2017, 271–72)

Relatedly, Hudson argues that our knowledge and understanding of endo is limited by an “epistemology of ignorance”—a term coined by Charles W. Mills (Hudson 2022; Mills 1999). Despite having a similar social and economic disease burden as conditions such as diabetes and asthma, endo has received less attention in government policy and research funding globally (Hudson 2022, 21). It has been dubbed “the missed disease” due to its unclear etiology and ambiguity in identification and classification. Hudson uses the concept of “undone science” to demonstrate that a lack of knowledge is the result of structural, cultural, and political processes that privilege certain voices, communities, and forms of knowledge while marginalizing others. She notes that the historical constructions of menstruation and women’s pain continue to influence contemporary imaginaries, often holding women accountable for their own illnesses. Through her analysis, Hudson argues that practices of ignorance and invisibility still shape the political and social landscape of endo.

While Hudson describes an epistemology of ignorance at the collective level of medical knowledge, my interviews show that, on the individual level, this is manifested as not knowing, having “weird” unexplained symptoms linked to a low-status “women’s disease,” or being perceived as “hysterical.” These are examples of how endo episteme appears in the lifeworld of interviewees. I suggest such experiences have an impact on interviewees’ epistemic self-esteem, making them feel that their endo experience is unimportant, low-status, or incomprehensible. These descriptions demonstrate what it is like to have experiences that are not satisfactorily taken up in shared hermeneutical resources, which makes it difficult to make sense of their experience (Fricker 2007).

Let us discuss the second epistemic practice, which can be read as a response to the epistemology of ignorance. I call this practice “epistemic activism,” a term borrowed from José Medina (2012). Many interviewees engage in activism to raise public awareness and knowledge about endo. For example, they join demonstrations, engage in social media patient groups, or become members of organizations like the Endometriosis Association (Endometriosisföreningen 2022) in Sweden. The Endometriosis Association focused its attention for several years on convincing the state to release national guidelines for the treatment of endometriosis. This objective was finally achieved in 2018 (National Board of Health and Welfare 2018). This fight for national guidelines can be considered a macro-political struggle—in which interviewees participate—in addition to the micro-political struggle of the medical encounter (Banks and Prior 2001).

Today’s endo activism should be seen in the context of the wider women’s health movement that emerged across the Western world in the 1970s and 1980s. This movement has been identified as an important site for feminist struggles to challenge ignorance and androcentric epistemologies (Tuana 2006; Whelan 2007; Hudson 2022). In “The Speculum of Ignorance: The Women’s Health Movement and

Epistemologies of Ignorance,” Tuana (2006) describes the movement as an example of an “epistemic resistance movement” that actively resisted “epistemologies of ignorance.”

According to Tuana, the movement aimed to provide women with basic medical knowledge, uncover the ways women were ignored, and develop new knowledge about women’s bodies and health. Its ultimate goal was “to take our bodies back from the institutions of medicine and reframe our knowledge and experiences of our bodies in ways not configured by sexism and androcentrism” (Tuana 2006, 2). Tuana discusses various examples, including the redefinition of menopause, the anatomical knowledge of the clitoris, and the feminist practice of genital self-exam using plastic speculums. She also mentions the importance of publications like the “women’s health bible” *Our Bodies, Ourselves* (Boston Women’s Health Book Collective 1973), and essays such as *The Myth of the Vaginal Orgasm* (Koedt 1970). These strategies aimed to resist ignorance and to encourage women to become “embodied knowers.” They wanted to augment women’s lives by transforming the knowledge about their bodies. For Tuana, the women’s health movement demonstrates how resistance movements can be useful sites for understanding how to identify, critique, and transform ignorance.

Similarly, in addition to raising public awareness, many interviewees report how groups on social media enable them to learn about the variety of experiences, thus enabling comparing-with: “Some have it like me, pain all the time, every day, and others mostly in connection with menstruation. It’s individual.” Interviewees describe groups on social media as essential for emotional support, which can be especially important if such epistemic support is lacking in one’s immediate social circle. Additionally, endo communities are discussed as important sources of medical knowledge: “Everything I know [about endo], I’ve learned online by reading in forums written by people with endometriosis themselves. Because the doctors knew nothing.” In the words of another interviewee, groups provide “a chance to discuss with people who are not totally incompetent in relation to endometriosis—ha!” These are all examples of how interviewees identify, critique, and transform ignorance and develop embodied knowledge by sharing experience and medical knowledge. They illustrate the concepts of “expert patients” and “internet-informed patients,” which blur the boundaries between forms of knowledge that otherwise separate patient and doctor, as well as blurring experience and expertise (Banks and Prior 2001; Horton-Salway 2004; Shaw 2002).

The interviewees’ descriptions generally align with Emma Whelan’s study of endo support groups as “epistemological communities” (Nelson 1993; Whelan 2007). The central role of experience in patient movements has been recognized before, but Whelan argues that these communities also redefine what counts as knowledge. Whelan states that the dominant epistemic principles in the community are “(1) that

patients form a community of sufferers who share common perspectives and experiences; (2) that these communal perspectives and experiences are valid forms of knowledge; and (3) that the only people who truly know endometriosis in an intimate way are those who suffer from the disease” (Whelan 2007, 978). Like the broader women’s movement, the endo communities described by interviewees are examples of epistemic activism aimed at challenging and overcoming an epistemology of ignorance. The interviewees’ experiences illustrate the inevitable connection between a group’s struggle to become knowers and to transform the knowledge available about them. By transforming knowledge, endo patients can ultimately overcome hermeneutical marginalization and secure a sense of epistemic self-esteem.

Concluding Discussion

The social recognition of endo is an important feminist issue. While some research has been done on the epistemic aspects of endo, not much attention has been given to the diagnostic journey and issues of recognition. I contribute to this area by providing a detailed description of the epistemic practices involved in the journey toward knowledge of endo—the practices that constitute *endo episteme*. I set out to answer the following questions: How do interviewees come to know endo? How is knowledge gained, negotiated, or lost? What are the implications for interviewees’ relation to self? To achieve this objective, I have used Fricker’s and Honneth’s theories—specifically the notions of epistemic support, respect, and esteem—to conceptualize crucial epistemic processes in the lifeworld of interviewees.

The first process demonstrates that *becoming a knower* of endo is highly relational. Concrete others are needed in two key senses: for comparing-with and expressive uptake. The second process involves *becoming a patient*, which is characterized by encountering a pedagogy of pain and responding with a struggle for diagnosis. Finally, the process of *becoming knowledge*, which concerns the collective level of shared hermeneutical resources, is characterized by an epistemology of ignorance and the efforts to overcome ignorance through epistemic activism. I understand the practices of comparing-with and expressive uptake as essential for *gaining* knowledge. The pedagogy of pain and the epistemology of ignorance are examples of how knowledge is *lost* rather than gained—in the sense of creating lost opportunities for learning. The struggle for diagnosis and epistemic activism can be understood as active attempts to *negotiate* knowledge, overcome ignorance, and push through epistemic obstacles.

Lack of epistemic recognition impacts the interviewees’ relation to self. When interviewees lack epistemic support, it can affect their sense of truth and their ability to individuate their feelings and experiences. This can undermine their epistemic self-

confidence and agency, making it more difficult for them to take the next step of seeking medical attention. When interviewees experience severe symptoms but are not recognized as patients, they begin questioning themselves and their own sanity—their epistemic self-respect is undermined. Conversely, receiving a diagnosis becomes proof that they are not “insane” and that their symptoms are not “all in their head.” Lastly, when interviewees’ symptoms are regarded as “weird” or related to “trashcan diagnoses,” it harms their epistemic self-esteem in the sense that they are hermeneutically marginalized with regard to their own experience. These examples illustrate how epistemic injustice can affect the knower’s sense of self and not just their knowledge.

The three modes of epistemic recognition have played a crucial role in identifying the processes and practices of endo episteme. By conceptualizing these practices, I have enriched the framework provided by Fricker and Honneth, introducing novel concepts that help us make sense of the interviewees’ experiences. This contribution to feminist and social philosophy can potentially be useful to interrogate other experiences characterized by misrecognition and epistemic injustice. By providing a language to describe common experiences, we can begin to analyze and address them politically. A central example used by Fricker is how the concept of “sexual harassment” made it possible to describe what had long been experienced. Relatedly, endo episteme illustrates how knowledge is of central concern for the misrecognition of an illness affecting millions worldwide. This way of creating concepts from the lifeworld demonstrates the significance of engaging with the complexities of “real-world political philosophy” (Wolff 2015, 22) and “messy empirical reality” (Zala et al. 2020).

Conceptualizing the practices of endo episteme also makes it easier to offer some clues for remedy and insights on “what should be done here and now” (Zala et al. 2020, 37). Fricker (2018, 4) notes, “One of the intellectual riches of recognition theory is that it offers something positive—an account of interpersonally generated positive self-confidence, self-respect, and self-esteem, directing our attention to the social relations and arrangements that encourage, nurture, and protect them.” Firstly, endo episteme highlights the importance of epistemic support from family and friends—of showing others “epistemic love” (Congdon 2018). If such support is missing, it becomes even more essential that other areas like schools and health care systems offer uptake, support, and respect in addition to information. Secondly, endo episteme demonstrates the significance of spreading available knowledge, such as creating national treatment guidelines to improve medical practice. The epistemology of ignorance also indicates the need to expand medical knowledge, which is dependent on research funding. As endometriosis still lacks a cure and is not well understood, increasing knowledge in this field is crucial. Thirdly, endo episteme highlights the importance of transforming social norms and biases regarding

menstruation and pain. This is a challenging task, but it is vital because lost opportunities for knowledge can result in years of delayed diagnosis and treatment. It is essential to educate young people that menstrual pain can be pathological and should not be considered normal. The pedagogy of pain needs to be *unlearned* collectively, and doing this requires information directed at adolescents. Such initiatives can potentially reach and target society's shared epistemic resources to prevent future generations from normalizing pain.

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INA HALLSTRÖM is a PhD candidate at Stockholm University, Sweden. Her current research focuses on the impact of gender and social recognition on experiences of illness. She aims to advance empirically driven theory development through her work. She is the author of "Endo Time: Endometriosis and the Flow of Recognition" (2024), published in *Hypatia*.