

Recognizing Endo

How Gender and Recognition Shape Experiences of Endometriosis

Ina Hallström



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Abstract

Endometriosis is a common and painful condition affecting millions worldwide. In recent years, it has also emerged as a site of gender justice struggles. This thesis offers an empirically informed phenomenology of this frequently overlooked condition, interpreting patients' experiences and demands for change as a contemporary struggle for recognition.

Based on in-depth interviews with 15 individuals in Sweden diagnosed with endometriosis, the study aims to deepen the understanding of how gendered dynamics and processes of recognition shape lived experiences of the condition. The analysis draws on the Hegelian concept of recognition, primarily as developed in Axel Honneth's recognition theory, to examine how recognition shapes relations to self and others and motivates struggles for change. Approaching endometriosis as the phenomenon of "endo," the thesis develops empirically informed concepts that capture its characteristic manifestations in the interviewees' lifeworlds. These concepts are elaborated across three articles.

The first article (I) introduces the notion of *endo time*, analyzing how the recognition of endo appears as a specific orchestration of time, in experiences of waiting time, cyclical or chronic time, and sedimented time. The second article (II) develops the concept of *endo episteme*, examining how recognition and everyday epistemic practices shape the journey to diagnosis and treatment, including the processes of becoming a knower, becoming a patient, and becoming knowledge. The third article (III) articulates *endo politics*, exploring how quests for diagnosis and treatment evolve into a struggle for recognition that involves developing a fighting spirit, becoming a "we," and struggling to be included.

Through these themes, the dissertation makes both empirical and theoretical contributions to gender studies, endometriosis research, and contemporary philosophical debates on gender and recognition.

Keywords: *chronic illness, endometriosis, gender, phenomenology, recognition.*

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This thesis is based on the following articles, which are referred to in the text using the concepts introduced in their short titles.

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INTRODUCTION

“Eight years is not OK!”¹

This slogan appeared on a large banner carried through central Stockholm during the Worldwide EndoMarch in 2017. Organized by the Swedish Endometriosis Association, the event highlights the long delays in endometriosis diagnosis and calls for standardized guidelines for endometriosis care. Since 2014, similar marches have taken place each March in cities around the world, with Sweden joining the movement in 2015.² The organization behind this global movement, now spanning more than 60 countries, describes its mission as a fight for “urgently-needed improvement to the way we diagnose and treat endometriosis, a potentially crippling, whole-body chronic disease, affecting an estimated 200 million people around the world” (Worldwide EndoMarch 2024). The movement calls for greater recognition of a common but frequently overlooked condition affecting roughly one in ten menstruating individuals – around 200 million girls, women, transgender, gender-diverse, and intersex people worldwide.³ In doing so, it raises broader questions about how experiences of illness are acknowledged, interpreted, and taken seriously within society.

Endometriosis is defined by the growth of tissue similar to the lining of the uterus outside the uterus. This tissue attaches to nearby organs and can cause severe pain and subfertility (Allaire et al. 2017; P. De Nardi and Ferrari 2011; Iacovides et al. 2015). Despite its severe symptoms and impact on quality of life, the path to diagnosis is often long. International studies report delays of up to a decade between the onset of symptoms and diagnosis (Ballard et al. 2006; P. De

¹ In Swedish: “Åtta år är inte OK!”

² The Swedish Endometriosis Organization was established in 1989, well before this.

³ The World Health Organization (WHO 2025) estimates that 10% (190 million) of reproductive age women have endometriosis. The prevalence among transgender, gender-diverse, and intersex individuals is unknown, and population-level statistics often exclude these groups. A systematic review found that the pooled prevalence of endometriosis is higher in transgender men (25.14%) compared to cisgender women (5-10%) (Okita et al. 2021; Giacomozzi et al. 2024, 2026). In rare cases, endometriosis has also been observed in cisgender men, typically in cases involving estrogen therapy for prostate cancer, or in individuals with liver disease or cirrhosis (Schrodt et al. 1980; Jabr and Mani 2014).

Nardi and Ferrari 2011; Seear 2009c). These delays contribute to substantial underdiagnosis and undertreatment (Iacovides et al. 2015). Highlighting the consequences of such delays, Katja Vatanen (2017), former chair of the Swedish Endometriosis Association, remarked, “Eight years is enough to ruin bodies, careers, relationships, and lives.” Her words capture the profound consequences of diagnostic delay and the urgency of addressing it.

Although endometriosis was first identified microscopically in the 1860s, its cause remains unknown and there is still no cure (Giudice and Kao 2004; WHO 2025). In medical literature, the condition is often described as an enigma due to the limited understanding of its causes and mechanisms. Despite disease and economic burdens comparable to those of conditions such as diabetes and asthma, endometriosis has received far less attention in government policies and research funding worldwide. Medical sociologist Nicky Hudson (2022) argues that this knowledge gap reflects structural, cultural, and political processes that marginalize endometriosis and render it nearly invisible. In this sense, the condition exemplifies what scholars call “undone science” and “wilful ignorance” – a fate endometriosis shares with many other gendered conditions. In light of this persistent neglect and the frequent dismissal or hysterization of patients, some scholars suggest that endometriosis should be understood not only as a biological condition but also as a social pathology (Jones 2015; Seear 2014). This perspective highlights the entanglement of biological and social dimensions, particularly the interplay between bodily pain and society’s systemic disregard for it.

Encounters like the EndoMarch in Stockholm sparked my interest in endometriosis. I began to notice its increasing presence in media coverage, on social platforms, and in personal testimonies describing both the suffering it causes and the way it can limit people’s lives. For a long time, endometriosis remained relatively unknown in the public sphere, but it appeared to be on the verge of entering public awareness. Having previously studied the experiences of women excluded from Swedish sickness insurance, I became increasingly interested in the intersection of three themes: gender, pain, and social recognition. These elements converge in the context of endometriosis, making it significant not only in its own right but also as a case reflecting broader societal concerns. It seemed important to explore the nature of this phenomenon, which can not only lead to multiple organ damage but is often experienced as “a disease of multiple losses: of relationships, of career and of a sense of self-worth” (Cox, Henderson, Wood, et al. 2003, 62). I began to wonder about the classic phenomenological question of what it is like (Zahavi 2005, 15) to live with endometriosis in a country like

Sweden, often seen as a utopia of gender equality and even described as “the world’s best country for women.”⁴

As illustrated by the endo marches in Sweden and beyond, endometriosis is increasingly articulated as a political issue. The global marches highlight that endometriosis is tied to broader societal concerns about gender, health, and justice. The aims of the movement align with the World Health Organization’s (WHO 2019a) focus on health equity, defined as the “fair opportunity for everyone to reach their full health potential.” Achieving fair opportunity requires understanding existing gender disparities and how individuals living with illnesses perceive their life situations. Previous research shows that gender norms and relations shape access to healthcare and influence health outcomes throughout the life course (WHO 2019c). Research on endometriosis indicates that living with endometriosis involves emotional, relational, and social dimensions that complicate its diagnosis and treatment. Many individuals struggle to have their experiences with endometriosis acknowledged and taken seriously by others. Despite this recurrent theme, recognition has rarely been a central focus in research on endometriosis.

Why does recognition matter? Since the 1990s, recognition has emerged as a central topic in discussions of social justice, illuminating the factors that motivate social movements. Theories of recognition, rooted in the philosophy of G.W.F. Hegel, view recognition as a fundamental human need that shapes our relations to ourselves and to others. Simone de Beauvoir’s ([1949] 1956) account of woman as the perpetual “Other” builds on and reinforces Hegel’s insights, showing how gendered social status is profoundly shaped by how we are recognized. Building on this tradition, I draw on Axel Honneth’s (1995) phenomenology of recognition to analyze the role of recognition in experiences of endometriosis. In Honneth’s framework, recognition is experienced in everyday interactions – through being loved and cared for, respected, and socially esteemed. These experiences confer social standing and shape what Honneth calls our practical self-relation: the socially mediated consciousness or feeling we have of ourselves, as reflected in our self-confidence, self-respect, and self-esteem. Recognizing someone as the bearer of certain rights – such as the right to health – grants them a normative status that obliges others to treat them accordingly. Recognition thus has both psychological and normative implications, shaping not only personal

⁴ The quote comes from an article on gender equality country rankings in *The Local* (2017), a newspaper providing news about Sweden in English. Sweden ranks first in the EU on the Gender Equality Index and has held its leading position since 2010 (European Institute for Gender Equality 2024). It also regularly ranks among the top ten countries in the Global Gender Gap Report (World Economic Forum 2025) and was ranked as the “best place to be a working woman” in *The Economist’s* 2025 glass-ceiling index (The Economist Group 2025).

identities but also our shared social world. Honneth (1995) argues that social conflicts often arise from everyday experiences of misrecognition and disrespect. This insight resonates strongly with reports from people living with endometriosis. By closely analyzing such experiences, we can discern what Honneth calls the “moral grammar” underlying social conflicts.

Despite its relevance, the potential of recognition within gender studies remains underexplored. While it is easy to conclude that recognition is a vital aspect of endometriosis experiences, there is much more to unpack about how it concretely shapes them. Focusing on recognition in the context of endometriosis can help illuminate how processes of recognition make certain experiences possible – and how their absence can harm an individual’s self-relation. This perspective enables an exploration of how struggles over the interpretation of pain become struggles for recognition. By viewing endometriosis not only as a medical condition but also as a site where such struggles unfold, this dissertation examines how gender dynamics and processes of recognition shape lived experiences of endometriosis.

Research Aim and Questions

The aim of this study is to deepen the understanding of how gender dynamics and processes of recognition shape lived experiences of endometriosis. Based on an empirical interview study conducted in Sweden, the dissertation identifies and thematizes experiences to contribute to both empirical knowledge and philosophical theorizing.

A central goal of gender studies is to understand how gender, as a social relation, is woven into the fabric of daily life – shaping social norms, subjectivities, and experiences. I use the term *gender dynamics* to refer to the complex of norms, relations, interactions, and subjectivities tied to sociohistorical conceptions of gender that shape lived realities. These dynamics are not fixed but evolving, material, and relational, involving multiple power differences. By exploring endometriosis through the lens of recognition, I adopt a bottom-up approach to theorizing justice. The analysis begins from the “messy empirical reality” and the non-ideal conditions that individuals living with endometriosis face. Focusing on their struggles and wishes, I develop a form of real-world political philosophy that uses philosophical concepts such as recognition to analyze social problems, identify social inequalities, and propose remedies.

The study draws on in-depth interviews with 15 individuals in Sweden who have been diagnosed with endometriosis. Drawing on these narratives, I develop

a phenomenology of their experiences, *identifying*, *describing*, and *analyzing* their general characteristics and typical features. In doing so, I approach endometriosis as the lived phenomenon of “endo” – a term that captures its various manifestations in the interviewees’ lifeworlds. The central research question guiding the study is: How can empirically informed philosophical inquiry clarify the interplay between gender, recognition, and self in the context of endometriosis, thereby advancing empirical knowledge and philosophical theory? This question is divided into three themes of inquiry:

- I. How do gender dynamics and recognition processes within the interviewees’ lifeworlds shape their experiences of living with endometriosis (endo), and how do these experiences affect their self-relation and motivation to change personal and collective circumstances?
- II. How can these experiences be thematized by identifying generalities and typical features in the interview narratives?
- III. How can we create empirically informed concepts from these narratives to develop more nuanced theories on endometriosis, gender, and recognition?

By presenting a phenomenology of the interviewees’ experiences, the study addresses these questions and articulates empirically informed concepts that reflect lived realities. The dissertation unfolds through an introductory part and three articles.

The introductory part outlines the theoretical framework, methodological approach, and empirical material underpinning the study. It also situates the project within existing scholarship on endometriosis, gender, and recognition and summarizes the three articles. These explore different aspects of the interviewees’ experiences of living with endometriosis and examine how gender dynamics and processes of recognition shape their lifeworlds and self-relations. Together, the articles develop empirically informed concepts that contribute to gender studies, endometriosis research, and contemporary philosophical debates on gender and recognition. The concluding chapter synthesizes the findings and reflects on their implications for policy and future research on endometriosis, gender, and recognition.

BACKGROUND AND RESEARCH CONTEXTS

This chapter situates the present study within relevant research contexts, emphasizing three core themes: endometriosis, gender, and recognition. It begins with a brief history of the medical understanding of endometriosis, summarizes qualitative research findings on the experiences of those affected, and discusses the emerging field of feminist research on the condition. The section on gender outlines the academic home and perspective of the study, highlighting its connection to feminist phenomenology related to the body and illness. Finally, I argue that this study makes a significant contribution by specifically addressing and theorizing the issue of recognition. In other words, I outline what is known, what remains to be learned, and how this study advances current understanding.

Understanding Endometriosis

A Brief History of the Medical Understanding of Endometriosis

Collaboration between patients and medical professionals has been pivotal in advancing knowledge about endometriosis. One important example is the founding of the Endometriosis Association in the United States in 1980, when patients joined physicians and scientists to establish the world's first self-help organization dedicated to the condition. Co-founded by Mary Lou Ballweg, the association immediately began the first systematic epidemiological studies of endometriosis (Ballweg 2010).

The first scholarly book offering a detailed medical history of endometriosis, *A History of Endometriosis*, was published in 2011 by medical scholar Ronald Batt (2011). Batt traces the evolution of medical knowledge of the condition from its first microscopic identification by Karl von Rokitansky in 1860. Batt explains that the development of anesthesia in the late nineteenth and early twentieth centuries opened new medical possibilities. In particular, it enabled a shift from autopsy to surgical pathology, which significantly improved physicians' ability to study endometriosis in living patients.

One particular patient played a central role in shaping this emerging medical understanding. Batt recounts how the medical understanding of menstruation changed radically, thanks to an unnamed 39-year-old nurse. In 1913, after two years of continued excessive menstruation, the nurse underwent a hysterectomy performed by the physician DeWitt Casler. Before surgery, however, she insisted that not all her ovarian tissue be removed because she was afraid that this would cause an “artificial menopause” (Batt 2011, 124). Following the surgery, the nurse reported that she continued to experience monthly bleeding. Casler initially dismissed this claim as impossible, since her uterus had been removed:

[T]he patient consistently maintained that at regular monthly intervals she menstruated for a part of one day each month. Just as constantly I assured her she must be mistaken, for a panhysterectomy had been done and menstruation was out of the question (Casler quoted in Batt 2011, 125)

A few years later, the nurse presented with severe cramping pains and constipation. A subsequent surgery revealed a semicystic tumor “the size of a grapefruit” (Batt 2011, 125). The surgery led to the realization that there were other “menstruating organs” besides the uterus.

This important case subsequently inspired the gynecologist John A. Sampson, a professor in New York, to search for similar cases of perforating hemorrhagic cysts. In 1921, Sampson introduced his first theory of endometriosis, describing cysts that perforated the ovary and bled into the pelvis. According to Batt, this represented a major shift in understanding: “The ovary became the organ of primary interest. Terminology changed. Adenoma replaced adenomyoma. The adjective ‘endometrial’ replaced the phrase ‘of uterine mucosa.’” (Batt 2011, 145). Although this marked an important first breakthrough, Sampson became best known for his subsequent theory that endometriosis results from “retrograde menstruation.” According to Batt (2011, 140), the early insights generated by the case of the “menstruating ovary” rapidly led to further discoveries:

During the feverish pace of research that followed, Sampson generated the second of three insights, retrograde menstruation and implantation, that would ultimately lead to his mature theory of implantation endometriosis. The third insight, spread by lymphatic and venous metastases, came from his realization that endometriosis shared many characteristics of cervical, endometrial, and ovarian cancer.

Despite early descriptions of endometriosis in the 1860s and Sampson’s influential theory of retrograde menstruation from the 1920s – which still prevails today – the precise etiology or cause of the disease remains unknown, and there is still no cure.

The history of endometriosis can be linked to broader shifts in cultural and scientific views, such as the changing perceptions of sex described by Thomas W. Laqueur (2018). Laqueur famously describes that in the ancient one-sex model, women were essentially perceived as flawed versions of men. However, by the 18th century, this perspective evolved into a two-sex model and an understanding of sex based on two distinctly different categories. Another significant development was the evolution of gynecology, or “The Science of Woman.” Like the first descriptions of endometriosis, the history of gynecology in Sweden can be traced back to the 1860s, a period characterized by a strong desire to explore everything there was to know about the female body. This is reflected in a growing interest in depicting female embodiment through art, medical textbooks, and advertisements. While men had served as the model for human embodiment, women were seen as different and in need of their own specialized area of study (Nilsson 2005).

In her investigation of the development of gynecology in Sweden during *la belle époque*, Ulrika Nilsson (2005) notes that in the 19th century, the womb was considered the primary symbolic source of womanhood. By the end of that century, this symbolic significance gradually shifted to the ovaries, driven by increasing knowledge about their role in menstruation. Half a century later, the concept of womanhood evolved again and became increasingly associated with hormones. These shifts in the symbolic representation of key body parts were linked to broader cultural ideas about gender and sexuality. Nilsson notes that the boundary between pathological and healthy was often unclear in relation to women. Women were thought to be less sensitive to pain because of the natural states of their bodies. The writings of Swedish physicians from this era describe pain as a “natural” aspect of female bodies, emphasizing the naturally painful process of childbirth. Even bleeding, typically regarded as pathological, was seen as more natural in women because of its link to menstruation (Nilsson 2005, 98).

As will become evident in later chapters, these ambiguous boundaries between what is considered normal and pathological continue to present a significant challenge for today’s endometriosis patients. Despite longstanding medical curiosity about the female body and despite the condition’s prevalence, endometriosis remains underdiagnosed and undertreated (Iacovides et al. 2015). Since there is currently no cure, treatment primarily focuses on symptom management. The two primary options are surgical removal of the lesions and medical therapies, which typically involve non-steroidal anti-inflammatory pain relief drugs and hormonal treatments intended to slow disease progression. This historical trajectory also helps explain why the experiences of people living with endometriosis continue to be shaped not only by biomedical knowledge but also by broader social processes of interpretation and recognition.

Negative Impact on Quality of Life: Delay, Normalization, and Lack of Support

While medical research has focused primarily on the biological mechanisms of endometriosis, a growing body of literature examines how the condition affects the everyday lives of those who live with it. The most common symptoms of endometriosis are severe pain and infertility. The condition can cause a wide range of pain symptoms, including *dysmenorrhea* (pain at menstruation), *dyspareunia* (pain at intercourse and penetration), *dyschezia* (pain at defecation), *dysuria* (pain at urination), and chronic pelvic pain (Della Corte et al. 2020). Symptoms can occur throughout the life cycle, starting at *menarche* (the first menstruation), continuing during adolescence, through adulthood, and even after menopause (Jackson and Telner 2006).⁵

Research consistently shows that endometriosis has wide-ranging effects on quality of life, including physical, psychological, and social effects. Studies indicate that the condition negatively affects education, work, sexual life, planning for and having children, and social relationships. It also carries a significant economic burden for both individuals and society due to losses in productivity and extensive use of health resources (Culley et al. 2013; Della Corte et al. 2020; Simoens et al. 2012). Steven Simoens et al. (2012) find reduced quality of life in all eight dimensions of the SF-36v2, a questionnaire commonly used to measure health-related quality of life (HRQoL), compared with norm-based scores from the general US population.⁶ Despite the evidence of declines in health and quality of life, there is a noted lack of qualitative studies on patient experience, as most studies focus on diagnostic techniques, clinical symptoms, and laboratory findings (Denny and Khan 2006; K. Young et al. 2015).⁷ The following sections outline key themes identified in qualitative research that address patient experiences. A systematic review by Kate Young et al. (2015) analyzed qualitative studies on experiences of endometriosis, identifying 11 studies published in English in peer-reviewed journals. The review highlights four key themes: *life*, which includes impact on sex life, social life, and work life; *symptoms*, dominated by the experience

⁵ A recent review finds an incidence of post-menopausal endometriosis of approximately 2-5% (Secosan et al. 2020).

⁶ The eight dimensions of HRQoL measured are: physical functioning, role limitation due to physical problems, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, and mental health. The calculated effect of endometriosis on HRQoL was considered *large* for some of these dimensions (general health, social functioning, and mental role limitation) and *moderate* (physical role limitation and pain) or *small* (physical functioning, vitality, and mental health) for the others (Simoens et al. 2012).

⁷ Given the limited number of studies, it is somewhat surprising to encounter a qualitative study of the impact of endometriosis on *male partners* (Culley et al. 2017).

of pain and infertility; *medical experience*, focusing on diagnostic delay, normalization, experiences of treatments, and doctors' lack of knowledge; and the *self*, noting that the impact of the illness on patients themselves is rarely reported, but when it is, themes revolve around the gaining of knowledge, emotional well-being, and worry about the future. The review stresses adverse effects on emotional well-being, with patients often feeling "weary," "miserable," "angry," and "depressed." Importantly, Young et al. (2015, 231) note that the detrimental effects on well-being stem not only from symptoms but also from how patients are treated by others:

[W]omen's sense of well-being was reduced not only by their symptoms but by the ways in which others (health professionals, partners, family, friends and colleagues) related to them and their condition. Particularly harmful were those health care professionals who defined the symptoms as representing poor mental health, often crudely labelling women as "crazy" or "depressed."

The review also indicates significant evidence gaps in the literature. These include limited research on the experiences of individuals with endometriosis-associated infertility and how reduced social participation affects perceived support and emotional well-being. In addition, there is limited knowledge of the experiences of adolescent and post-menopausal women, women from socioeconomically disadvantaged backgrounds, non-heterosexual women, and women who do not identify as Caucasian (Young et al., 2015).

One of the most frequently discussed topics in endometriosis research is the period leading up to diagnosis. It is widely acknowledged that people with endometriosis experience substantial delays before receiving their diagnosis (Ballard et al. 2006; Cox, Henderson, Wood, et al. 2003; Seear 2009c). This delay continues to be a prevalent issue, leading to extended periods of pain, uncertainty, and distrust (Seear 2009c). Elaine Denny (2009) notes that this uncertainty concerns the diagnosis itself, the disease course, and what the future holds for patients. In Sweden, the average time to diagnosis is five to seven years (SBU 2018). This is concerning, as delayed diagnosis can increase the risk of both chronic pain and infertility (National Board of Health and Welfare 2018, 13). Research indicates that gender-related delay is evident in many diseases. Westergaard et al. (2019) demonstrated that even in a country with equitable access to healthcare, the average age at the first hospital diagnosis was nearly always higher in women.

One important explanation for delayed diagnosis is the normalization of symptoms by both patients and healthcare providers (Ballard et al. 2006; Cox, Henderson, Andersen, et al. 2003; Manderson et al. 2008). Symptoms are often dismissed as just "bad luck" with menstrual cramps, viewed as a normal part of

menstruation and womanhood, or something patients need to cope with on their own. This perception can lead patients to feel that their symptoms are “all in their head” (Ballard et al. 2006; Denny 2004). Consequently, obtaining an endometriosis diagnosis can validate their symptoms and provide the legitimacy needed to seek support from others (Ballard et al. 2006; Ballweg 1997).

Research drawing on Erving Goffman’s concept of social stigma highlights that women often view menstruation as a secretive and shameful process, perceiving their menstrual cycle as something negative. The stigma surrounding menstrual issues, along with the societal normalization of women’s pain, contributes to a lack of awareness of the disease among patients, healthcare providers, and the general public (As-Sanie et al. 2019). Although some research has explored stigma in relation to endometriosis, Omar T. Sims et al. (2021) argue that this topic remains insufficiently studied. They suggest that stigma significantly contributes to poor psychosocial well-being and delays in diagnosis.

Prior research also shows that communicating about endometriosis and gaining recognition for it can be especially challenging. Many individuals report feeling isolated and misunderstood by family, friends, and colleagues (Cox, Henderson, Wood, et al. 2003; Shah et al. 2010). In contrast, having a close friend or family member who took their complaints seriously has been noted as crucial for prompting women to seek medical care (Shah et al. 2010). Outside intervention can serve as a crucial “circuit breaker” and encourage help-seeking (Manderson et al. 2008). A recent qualitative systematic review on pain communication in endometriosis highlights the complexity of interactions between patients and healthcare providers. These encounters are often characterized by disbelief, normalization, and psychological attribution (Robstad et al. 2024). The review concludes that individuals with endometriosis carry a dual burden: they suffer not only from physical symptoms but also from the psychological weight of being disbelieved by healthcare professionals. Other recurring themes include difficulties in effectively communicating pain to others and a lack of mutual understanding between patients and clinicians. In this context, patient communities can become important spaces for validation and shared understanding. Emma Whelan (2007), drawing on Lynn Hankinson Nelson’s concept of “epistemological community,” analyzes the epistemological strategies used by members of an endometriosis patient community. Her study highlights the central role that experiential knowledge plays within these communities.

A few studies use phenomenological approaches to explore lived experiences. One study employing interpretive phenomenological analysis (IPA) describes a significant lack of knowledge, acceptance, and support for people with endometriosis (Clark 2012). Another study using Cohen’s phenomenology identifies four prominent themes: *delay in diagnosis, worsening of one’s life, disastrous intimate life with*

one's partner, and uncertainty about being able to have children. Delay in diagnosis is described not only as prolonging pain but also as making it harder for others to understand the seriousness of patients' experiences (Rea et al. 2020). These studies demonstrate that focusing on lived experiences reveals central concerns related to well-being, interpersonal interactions, and personal identity. However, while they employ phenomenology descriptively, they do not pursue the broader structural ambitions of phenomenological philosophy. In particular, they offer a limited theoretical analysis of the underlying structures shaping these experiences. Addressing such structures or typical features is one of the aims of the present study, as will be discussed further in the methodology chapter.

Within the Swedish context, two dissertations using qualitative methods have explored the topic of endometriosis.⁸ One of these is Hanna Grundström's dissertation, *Disclosing the Invisible: Experiences, Outcomes and Quality of Care* (2018). It consists of four articles that examine endometriosis healthcare in Sweden from a medical and health science perspective. One article specifically focuses on patients' perspectives regarding healthcare encounters, employing interviews analyzed through interpretive phenomenology. The analysis reveals two significant themes: firstly, *being treated with ignorance*, where the interviewees report feelings of exposure, disbelief, and facing ignorance; and secondly, *being acknowledged*, in which the interviewees felt confirmed, visible, listened to, and believed (Grundström et al. 2018). This article underscores the importance of being acknowledged in healthcare encounters. While Grundström's work focuses primarily on clinical encounters, the present study expands the scope to include other domains of the lifeworld, such as education, work, and personal relationships, with particular attention to the theme of recognition.

The second Swedish dissertation on endometriosis is by Ida Melander, entitled *Making Your Voice Heard: Discourses, Genres and Narratives in the Negotiation of Illness* (2022). This work is situated in Swedish Language studies and combines discourse analysis with social semiotics. It explores how individuals with endometriosis create meaning around their illness in three patient-oriented health-related contexts: online discussion forums, self-referrals for seeking specialist care, and illness narratives on Instagram. In a co-authored article, Melander and Björkvall (2022) also analyze emotions and affect in discourses on endometriosis across three venues: online discussion forums, Instagram, and newspapers. While this research provides valuable insights into discourse and communication practices

⁸ Some Swedish dissertations also investigate endometriosis from a medical perspective, for example, examining the immune system's role in the disease (Björk 2024; Alson 2024; Moberg 2017).

surrounding endometriosis in Sweden, it primarily focuses on discursive representations rather than on first-person lived experience, which is the central focus of the present study.

A Feminist Perspective on Endo

In addition to the qualitative studies discussed above, there is a small emerging field that explores the intersection of gender and endometriosis from a feminist perspective. Cara E. Jones notes that although there is considerable research into the cultural, medical, and political dimensions of women's bodies, there is a notable lack of feminist studies focusing on endometriosis as a cultural construct. This absence is particularly significant since, according to Jones, endometriosis has now "taken up a diagnostic and cultural location once occupied by hysteria" (Jones 2015, 1084).

By looking at medical and self-help literature on endometriosis through the lens of feminist body studies, Jones connects the hysterization of present-day endometriosis patients to historical myths surrounding the female body and womb. She notes that, akin to the ancient concept of the wandering womb – believed to roam the female body in search of children and shaping earlier understandings of hysteria – endometriotic tissue has sometimes been described as roaming the uterine lining (Jones 2015, 1083–84). Moreover, both conditions are characterized not only by pathological physical symptoms but also by deviation from traditional gender norms. Jones highlights that doctors have consistently linked endometriosis to departures from societal expectations of marriage and motherhood. She concludes that "a specter of hysteria's wandering womb haunts medical and self-help literature in the late twentieth and early twenty-first centuries, reinforcing traditional gender and social roles" (Jones 2015, 1084). This observation connects to a longer history in medicine of psychologizing or hysterizing women's health conditions that remain poorly understood or mark a departure from gender norms (Ussher 2005; Showalter 1987).

Beyond Jones' work, a small but emerging field of gender and feminist studies has begun exploring the social dimensions of endometriosis. This research highlights how gender norms shape both the interpretation and treatment of the condition and calls for critical feminist discussions that challenge the prevailing medical discourse. For instance, in her article "'Lasers for Ladies': Endo Discourse and the Inscriptions of Science," Ella Shohat argues that medical literature has conceptualized endometriosis in terms of disorderly female biology, behavior, and personality (Shohat 1992). Nicky Hudson discusses endometriosis as an example of undone science, characterized by an epistemology of ignorance – a term originally coined by Charles W. Mills (1999). Hudson notes that despite having a

social and economic burden comparable to that of diabetes and asthma, endometriosis has received significantly less attention in terms of policy and research funding globally. Due to its unclear etiology and inconsistencies in its diagnosis and management, endometriosis is often referred to as the “missed disease” (Hudson 2022).

Kate Seear has made several significant contributions to the field, including the book *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics* (2014). The book delves into the symbolic, discursive, and material dimensions of the condition, drawing on feminist theory, queer theory, and science and technology studies. In one of her articles, Seear explores the rationale behind patients’ non-compliance with healthcare advice. She finds that non-compliance often arises from patients’ subjective experiences of self-care and risk-avoidance as burdensome, excessive, impractical, time-consuming, and too costly (Seear 2009a). In second article, she argues that diagnostic delays are reinforced by broader cultural norms surrounding menstruation. She points to the role of menstrual concealment and what Sophie Laws (1990) calls “menstrual etiquette,” arguing that diagnostic delays and reluctance to disclose menstrual difficulties should be understood against the backdrop of fear of stigmatization (Seear 2009c). In a third article, Seear analyzes how endometriosis self-help literature depicts the self as both “ontologically separate from and superior to the body and as capable of mastering the accidental, uncontrollable and unpredictable event of illness” (Seear 2009b, 45).

These feminist interrogations of endometriosis have directly inspired my own research. Building on this emerging body of research, I focus on a dimension that remains relatively underexplored and undertheorized: recognition. By examining how processes of recognition shape the lived experiences of individuals with endometriosis, this dissertation contributes directly to the feminist scholarship on the condition.

Gender Studies and Feminist Phenomenology of the Body and Illness

While existing research on endometriosis provides valuable insights into the experiences of those affected, it has only begun to explore these experiences from a feminist perspective. There is still a significant need to contextualize these experiences within the framework of gender relations and power dynamics. Gender studies investigate how gender, as a social relation, manifests in various aspects of life, influencing norms, identities, institutions, and personal experiences. As an interdisciplinary field, gender studies draws on methods and theories from

multiple disciplines to analyze how gender structures social life. The present study combines gender analysis with empirically informed philosophy. Its central object of inquiry is the gendering of endometriosis, which is explored through empirical material generated from interviews. Phenomenology and recognition theory provide the philosophical framework through which these experiences are analyzed.

Feminist theory and philosophy have long examined how gender shapes understandings of the body. Scholars have explored the body in relation to sexual difference (Irigaray 1985b; Cavarero 1995), standards of beauty standards and bodily norms (Bordo 2004, 1993), and the intersection of gender and other social categories such as race, class, and dis/ability (Alcoff 2006; Kafer 2013; Collins 1990, 1998; Lorde 2007; hooks 1984). A recurring theme in feminist philosophy is the historical association of women with the body. Elizabeth Grosz (1994, 14), for example, observes that “[w]omen are somehow *more* biological, *more* corporeal, and *more* natural than men.” Beauvoir makes a similar point in *The Second Sex* ([1949] 1956, 13)⁹ when she writes, “what is a woman? ‘Tota mulier in utero’, says one, ‘woman is a womb.’” These formulations illustrate how women have historically been defined through their bodies and reproductive functions. Genevieve Lloyd (1996) argues that this perception can be traced throughout the history of Western philosophy, where concepts of reason and rationality have been constructed as male, while nature and the body have been associated with women. Elizabeth Spelman (1982, 109) similarly notes, “What philosophers have had to say about women typically has been nasty, brutish, and short,” linking their misogyny to a corresponding “somatophobia.”

Gender norms and relations also shape how specific bodily processes, like menstruation, are interpreted and experienced. Menstruation has long been associated with taboo, stigma, and societal expectations of concealment across various cultures, including in Sweden (Winkler et al. 2024; Johnston-Robledo and Chrisler 2013; Montgomery 1974; Åkerman et al. 2024; Malmberg 1991; Persdotter 2022).¹⁰ Religious traditions have frequently portrayed menstruation as impure, including in the Old Testament, the Quran, and practices within Hinduism and Orthodox Judaism. In 19th-century Sweden, women menstruating were even barred from participating in baptisms (Persdotter 2022, 20–21).

⁹ I am using both available English translations of *The Second Sex*, selecting the one I prefer for each quote. Although the Parshley translation (Beauvoir [1949] 1956) omits 145 pages and contains misleading translations of philosophical terms, it sometimes provides better readability in terms of punctuation and grammar. For a review of the Borde and Malovany-Chevallier translation (Beauvoir [1949] 2011) and a discussion of both, see Bauer (2011).

¹⁰ Margaret Mead (2001) provides an interesting exception by describing the Samoans she visited in the early 20th century as more comfortable discussing the topic of menstruation.

The cultural expectation that menstruation should remain hidden continues to shape everyday practices and language. Menstruation is often avoided in conversations, and a variety of euphemisms are employed worldwide to refer to menstruation, such as “the curse,” “the red plague,” or expressions like “I’m wearing red shoes today” or it’s “my time of the month” (Johnston-Robledo and Chrisler 2013). Media representations frequently reinforce negative stereotypes by depicting menstruators as irrational, overly emotional, or even violent in ads, newspapers, television shows, and in humorous products like greeting cards (Johnston-Robledo and Chrisler 2013). This stigma, coupled with the inclination to conceal the subject, creates barriers to open discussions of menstrual issues such as menstrual pain or heavy bleeding, both of which are common symptoms of endometriosis (Seear 2009c). Research on menstrual stigma therefore provides important context for understanding how endometriosis symptoms are interpreted and responded to. In the present study, these dynamics are further examined through the lens of social recognition.

Phenomenology has long provided philosophical tools for examining first-person experiences of the body and illness. Since its early development, phenomenology has explored the body not only as a biological object but also as a lived and meaningful dimension of human experience. Edmund Husserl’s distinction between the body as object (*Körper*) and the body as lived (*Leib*), as well as Maurice Merleau-Ponty’s *Phenomenology of Perception* ([1945] 2012), laid the groundwork for later phenomenological analyses of illness and embodiment (Carel 2016; Leder 1998; Svenaeus 2000). Feminist phenomenology has further developed these insights and explored various aspects of gendered embodiment and illness. This work includes analyses of menstruation, pregnancy, breasts, and other facets of female embodiment (Beauvoir [1949] 1956; I. M. Young 2005b; Heinämaa 2014), childbirth (Trigg 2021; Oksala 2004), illness and pain (Käll 2012; Fisher 2014; Käll and Zeiler 2014), breast cancer (De Boer et al. 2019), the meaning of embodiment in medical practice (Slatman 2014), body shame (Dolezal 2015b, 2015a), and aging and disability (Weiss 2014, 2017). By situating bodily experience within social and normative contexts, feminist phenomenology offers important tools for analyzing how illness is lived and interpreted.

This study contributes to the field of gender studies and feminist phenomenology in three main ways. First, it investigates gender relations within the specific context of endometriosis. Second, it demonstrates the value of employing phenomenology alongside the Hegelian concept of recognition in gender analysis. By understanding gender as both shaped by and shaping recognition processes, recognition theory offers a useful lens for analyzing the complex intersubjective dynamics involved in illness experiences. Finally, it provides a phenomenological analysis of endometriosis, an understudied phenomenon situated

at the intersection of gender and illness. In doing so, it highlights how gender dynamics and recognition processes shape the lived experiences of this gendered chronic condition, which is increasingly understood as a site of political struggle for gender justice.

The Research Gap: Recognition of Endometriosis

In summary, qualitative research has shown that endometriosis has profound effects on both the quality of life and emotional well-being of those affected. Many patients struggle with a lack of support and understanding, along with feelings of uncertainty about their condition. Studies consistently indicate that factors such as diagnostic delays, normalization of symptoms, and limited knowledge contribute to these distressing experiences. Importantly, research also demonstrates that the negative impact on quality of life is not solely due to physical symptoms. The way patients are treated by others plays a significant role in shaping their emotional well-being and sense of self-worth.

These findings underscore the vital importance of social recognition in shaping illness experiences and individuals' relations to themselves. Understanding endometriosis therefore requires attention not only to symptoms and treatments but also to the intersubjective processes through which experiences of illness are acknowledged, interpreted, and validated. Despite this need, there is a shortage of qualitative research on endometriosis experiences, and existing studies rarely engage explicitly with recognition as an analytical concept. While several studies point to the significance of being believed, supported, and taken seriously, they seldom analyze these dynamics in terms of recognition or explore their broader theoretical implications.

This study addresses this gap by examining the lived experiences of endometriosis through the lens of recognition theory. By focusing on social interaction, support, and the ways individuals' experiences are acknowledged or dismissed, the study deepens understanding of how recognition processes shape illness experiences and individuals' practical self-relations. In doing so, it revisits themes identified in previous research – such as diagnostic delay, normalization, and lack of support – while analyzing them as intersubjective processes structured by gendered relations of recognition. While some qualitative studies use phenomenological approaches to describe lived experiences, they typically employ phenomenology as a descriptive tool rather than as a philosophical framework aimed at analyzing the underlying structures of experience. The present study differs in this respect. It develops a phenomenology that seeks to identify typical features of endometriosis experiences while remaining grounded in

first-person narratives. Through this approach, the study develops empirically informed concepts that capture recurring patterns in the interviewees' experiences and contribute to endometriosis research, gender studies, and ongoing philosophical discussions on gender and recognition. The following chapter presents the theoretical framework that guides the analysis of these experiences.

GENDER AND RECOGNITION: A THEORETICAL FRAMEWORK

This chapter develops the theoretical framework used to analyze how gender dynamics and processes of recognition shape experiences of illness. At the heart of this analysis lies the concept of recognition (*Anerkennung*), developed by G.W.F. Hegel on the basis of Johann Gottlieb Fichte's ([1796] 2000) earlier work.¹¹ Hegel uses the concept to describe how individuals gain self-consciousness through processes of mutual recognition – an idea famously illustrated in the master-slave dialectic in *Phenomenology of Spirit* ([1807] 1977). Yet the concept extends beyond this well-known formulation. In his later work, Hegel ([1821] 1991) presents recognition as institutionalized within three spheres of society: the family, civil society, and the state.

Building on this understanding of recognition, this dissertation approaches endometriosis patients' experiences and demands for change as a contemporary struggle for recognition. Since the mid-1990s, the Hegelian theme of the "struggle for recognition" has become a prominent topic in discussions of social justice, particularly for understanding the motivations behind social movements (Fraser and Honneth 2003; Taylor 1994). Recognition theories generally treat recognition as a fundamental condition for developing and maintaining a positive self-relation. As social beings, individuals rely on intersubjective feedback to develop a sense of who they are. Recognition therefore has both psychological and normative dimensions. When we recognize specific qualities in others – for example their right to health and medical care – we adopt a positive attitude toward them and grant them a normative status as bearers of rights, which in turn commits us to treat them accordingly. In this way, recognition contributes both to identity formation and to the allocation of social standing. Moreover, these intersubjective processes link everyday experiences to broader social relations, including those related to gender.

¹¹ Both Fichte's and Hegel's discussions of recognition can be further traced back to Jean-Jacques Rousseau, who held a more negative view of society and distinguished between natural self-love (*amour de soi*) and a societal, vain form of self-love (*amour-propre*) that motivates individuals to seek esteem (see Neuhouser 2008).

Although Hegel was not a feminist philosopher, his work has nevertheless played a significant role in feminist debates about subjectivity, gender, and recognition. In particular, Simone de Beauvoir and Judith Butler both draw on and critically engage with Hegel's notion of recognition in their analyses of sex and gender. This intellectual lineage places Hegel – perhaps surprisingly – near the center of many debates in gender studies. While the work of Beauvoir, Butler, and others has been crucial for the development of gender studies, Hegel's concept of recognition still holds considerable untapped potential for analyzing gender relations.¹² Recognition theory is well suited to this task because it provides a framework for understanding the dynamic interplay through which individual self-relations and social relations develop over time (Hegel [1807] 1977; Honneth 1995). It also enables analyses of the role of affect and personal experiences in motivating struggles for social change. This perspective is especially relevant for exploring the relationship between gender and illness. As already mentioned, gender norms and values significantly shape both health outcomes and access to healthcare throughout the life course. Conditions that predominantly affect women remain underdiagnosed, undertreated, and underresearched (Mirin 2021). These patterns raise the question of how people living with gendered conditions such as endometriosis experience recognition in their everyday interactions. The theoretical framework developed here therefore places recognition theory in dialogue with feminist theory and phenomenology. This combination makes it possible to analyze how gender dynamics and recognition structure lived experiences of illness. I argue that these dynamics play a central role in shaping how endometriosis is lived, interpreted, and contested in everyday life.

In the following sections, I first present the philosophy of recognition developed by Axel Honneth, whose work offers one of the most comprehensive contemporary reinterpretations of this Hegelian theme. I then return to feminist engagements with Hegel – particularly those of Beauvoir and Butler – in order to address the question of how Hegel's ideas can be productively used within gender studies. Honneth (1995, 14) elaborates the Hegelian insight that “every philosophical theory of society must proceed not from the acts of isolated subjects but rather from the framework of ethical bonds, within which subjects always already move.” This view casts Hegel as fundamentally a social and relational thinker, emphasizing that individuals become who they are through their interactions with others. Recognition thus becomes a central concept in understanding the structures of social life. As Heikki Ikäheimo and Arto Laitinen (2011, 5)

¹² See also Federica Gregoratto who points out that although the concept of recognition has become a key idea in social and political philosophy, it has not yet had a similarly fruitful impact on debates within feminist, gender, or queer theory (Gregoratto 2015).

observe, recognition in Hegel's thought is "a central element of the psychological, social and institutional structures constitutive of the social world of persons. Thus, according to the original idea, recognition is a social ontological concept." Building on this insight, Honneth (2004) effectively reframes the notion of justice in terms of due or withheld recognition. This understanding provides valuable tools for analyzing how gender dynamics unfold through intersubjective interactions.

Honneth's Recognition Theory: Starting From the Struggles and Wishes of the Age

Honneth's theory of recognition forms the central philosophical framework for this study. As a third-generation representative of the Frankfurt School, Honneth develops recognition theory as part of a broader project within critical theory that seeks to connect philosophical analysis with contemporary social struggles.¹³ Before outlining the three forms of recognition that structure his theory – love, respect, and esteem – it is therefore necessary to explain how Honneth arrives at this model through his distinctive approach to critical theory. The relevance of critical theory to this study lies in its focus on power relations, injustice, and emancipatory goals, as well as its ambition to ground theory in contemporary social struggles and aspirations. Karl Marx (1843) famously captured this orientation when he described "the self-clarification (critical philosophy) of the struggles and wishes of the age," a formulation later echoed by Max Horkheimer ([1937] 1972, 231), who described critical theory as "the self-awareness of the subjects of a great historical revolution."

Building on this tradition, Honneth emphasizes the importance of bringing theory and practice together by identifying an emancipatory interest within social life. Critical theory, he argues, must seek to comprehend "both the structures of social domination *and* the social resources for its practical overcoming" (Honneth 1993, xiv).¹⁴ The contemporary struggles for diagnosis and treatment of endo-

¹³ The first generation includes Max Horkheimer, Theodor Adorno, and Herbert Marcuse, while the second is represented by Jürgen Habermas, and the third is often linked to thinkers like Nancy Fraser and Seyla Benhabib. The Frankfurt School of thought is connected to the Institute for Social Research in Frankfurt, where Honneth also served as director.

¹⁴ In a chapter introducing critical theory, Honneth (2008a, 788) describes its essence, with reference to Horkheimer, as "a critical form of reflection (...) on those social struggles and conflicts in which the up-to-now suppressed collective rises up against injustice and disadvantage." Moreover, in key figures of critical theory – Horkheimer, Adorno, Marcuse, and Habermas – Honneth (2008a, 793) finds the shared goal, stemming from Hegel, of identifying and critiquing social pathologies,

metriosis can be understood as exemplifying such “struggles and wishes,” representing both new expressions and continuations of earlier feminist and health social movements. Grounding the analysis in first-person narratives allows for a form of “self-clarification” akin to what Marx and Horkheimer envisioned, but with a specific focus on gender relations – a dimension often neglected in early critical theory (Fraser 1985). This self-clarification involves tracing an emancipatory interest within the experiences and practices described by the interviewees and developing empirically informed concepts that capture typical features of these experiences. In this way, it grounds social critique in the social practices surrounding endometriosis, combining empirical research with philosophical analysis – a core tenet of critical theory.¹⁵

I draw inspiration from Honneth’s (2014c) ambition to return critical theory to its left-Hegelian roots through the method of “normative reconstruction.” This method derives the standards for social critique from society itself, enabling an internal or immanent critique closely connected to social reality. Normative reconstruction can be contrasted with forms of “normative construction,” such as those associated with Immanuel Kant and early John Rawls, which have been criticized for creating external, abstract standards “high up in the thin air of philosophy” (Carleheden 2021, 302) and applying them to the social world only secondarily. In contrast, Honneth seeks to develop a distinctly social understanding of concepts such as recognition, justice, and freedom by grounding them in the shared ideals and values that already underpin social life. As he states, “I try to derive relevant criteria of social justice directly from the normative claims that have evolved within those spheres of action that are constitutive of modern societies” (Honneth 2015, 206).

This approach can also be understood in light of the common distinction between ideal and non-ideal theories of justice introduced by Rawls (1971). Ideal theories, from Plato to Rawls, are often criticized for focusing on abstract visions of a more or less perfectly just world while neglecting the role of social and political institutions and the complex histories of discrimination faced by specific groups (Zala et al. 2020). Because such approaches require little empirical input, they offer limited guidance for improving present conditions. Amartya Sen (2009) describes these approaches as “transcendent” theories of justice. By contrast, the non-ideal perspective adopted here – reflected in the work of Honneth, Sen (2009), Charles W. Mills (2005), and Miranda Fricker (2015) – begins with existing injustices and the imperfect conditions of social life. Like Zala et al.

which are “accompanied by a painful loss of chances with respect to intersubjective self-realization.”

¹⁵ Honneth (1993, 3) describes this tenet as “a philosophically guided diagnosis of the time (...) combined with an empirically grounded social analysis.”

(2020), I therefore start from the “messy empirical reality” of the interviewees’ experiences. My aim is a down-to-earth form of theorizing that connects the empirical with the normative. In this sense, the study resonates with Jonathan Wolff’s (2015, 22) notion of “real-world political philosophy,” which uses concepts like justice and recognition to analyze social problems, identify social inequalities, and propose remedies. Wolff points to Iris Marion Young (2011) as a prominent example of such an approach, and Honneth’s work can likewise be situated within this tradition.

Although Honneth remains close to Hegel’s insights, he seeks to move beyond Hegel’s metaphysical framework by replacing the idea of Spiritual (*Geistiges*) self-realization through history with an understanding of how norms evolve over time.¹⁶ Such evolution does not occur smoothly or without conflict. On the contrary, because normative ideas have the power to shape and reshape social reality, it is “in and through social struggles that their claims to validity come to fruition” (Honneth 2015, 207). Social actors, including the interviewees of this study, contribute to this transformation by “taking the promises implicit in historically formed norms at their word, and through trying to implement those promises by rebelling against prevailing social conditions” (Honneth 2015, 208). From this perspective, struggles for recognition are ultimately struggles to change society’s shared norms, including those shaping the recognition of a gendered condition like endometriosis.

By building on existing social conflicts and disagreements about societal norms of recognition, Honneth’s normative reconstruction distills the normative claims that participants in social struggles take as underlying specific social spheres. This involves extracting normative standards from current institutions and practices – “out of the chaos of social reality” – which can then serve as a basis for “reconstructive critique” to address gaps in the embodiment of widely accepted values (Honneth 2014c, 9). Honneth notes that the approach of reconstructive critique was already present in Hegel’s work, which extended beyond merely describing and affirming existing practices and institutions; he also aimed to correct and transform them.

In the context of endo, this perspective resonates strongly with the interviewees’ accounts of misrecognition and provides a framework for interpreting them. Their experiences frequently contradict widely endorsed societal “promises” of gender equality and the human right to health. Although ideals such as equality and fairness are formally acknowledged, the interviewees clearly indicate that they

¹⁶ Honneth describes the concept of Spirit as obsolete metaphysics and offers the following alternative: “I use the idea (ultimately derived from Sociology) that a certain class of the Spiritual [*Geistigen*] – namely, normative ideas – have the ability to shape and remodel social reality in accordance with their own content” (Honneth 2015, 207).

are not consistently realized in practice. Analyzing these experiences therefore provides a basis for critiquing how endometriosis is socially recognized, particularly by identifying experiences of misrecognition – situations in which well-founded expectations of recognition are unmet.

Starting from the interviewees' experiences also reflects Honneth's suggestion to look beyond the issues already raised in social movements and consider the everyday experiences of "social misery and moral injustice" that remain unthematized (Honneth 2003a, 113–14). Honneth argues that feelings of humiliation and disrespect form the "moral grammar" of social conflicts (Honneth 1995, 2014a).¹⁷ Drawing on John Dewey's action-theoretical account of human emotions, he suggests that disrespect "is always accompanied by affective sensations that are, in principle, capable of revealing to individuals the fact that certain forms of recognition are being withheld from them" (Honneth 1995, 136). When anticipated recognition fails to materialize, these affective reactions can give rise to "moral" conflicts within the social lifeworld and motivate struggles for recognition (Honneth 1995, 137). This perspective is particularly useful for analyzing the affective dimensions of the interviewees' illness experiences and their role in motivating social change.

Love, Respect, and Esteem

Honneth's theory of recognition is best understood through his view that the ultimate goal of social justice is to enable individuals to develop a positive personal identity, which depends on different forms of recognition. This development supports human flourishing – a condition described by Aristotle (2009) as *eudaimonia* and often invoked by Butler in discussions of the aims of politics.¹⁸

At the centre of Honneth's theory is the idea that identity formation depends on relations of recognition. A positive relation to oneself, he argues, requires ongoing support and affirmation from others. In developing this account, Honneth draws not only on Hegel but also on insights from social psychology and psychoanalysis, including Donald Winnicott's object relations theory, attachment theory, and George Herbert Mead's account of the social emergence of the "self"

¹⁷ Honneth uses the terms "grammar," "logic," and "structure" interchangeably to describe the internal logic of recognition and social conflict. In *The Struggle for Recognition: The Moral Grammar of Social Conflicts*, we find a Wittgensteinian moral "grammar" in the subtitle (see also Honneth 1995, 165–66), references to a Hegelian moral "logic" (Honneth 1995, 70, 144, 160, 165, 190), and discussions of "the normative claims that are structurally inherent in relations of mutual recognition" (Honneth 1995, 2).

¹⁸ Butler (2009, 20) often refers to the concept of flourishing, for instance, in describing the goal of politics as providing "the social conditions of persistence and flourishing."

through interaction. Taken together, these perspectives support an understanding of identity as a practical self-relation that develops through the gradual internalization of recognition from both concrete and generalized others.¹⁹ While Hegel famously described the relational emergence of self-consciousness, Honneth builds on these insights to formulate a more explicitly social theory of identity formation grounded in intersubjective recognition.

On this basis, Honneth (1995, 129) identifies *love*, *respect*, and *esteem* as three primary forms of recognition in modern societies.²⁰ Experiencing these forms of recognition contributes to the development of a positive practical self-relation expressed as self-confidence, self-respect, and self-esteem. This self-relation is practical because it underpins autonomy and agency and shapes how individuals relate to themselves in everyday life. Each form of recognition is associated with a main societal “sphere of action,” broadly reflecting the spheres that Hegel described as the family, the state, and civil society.

(1) *Love* involves the private sphere understood in a broad sense, including the care and emotional support found in close relationships of love and friendship. Recognition of this kind relates to our basic needs and emotions and is essential for developing and maintaining what Honneth describes as *basic self-confidence*. Negative experiences such as neglect, abuse, or rape can threaten our sense of emotional well-being and physical integrity, potentially destroying our self-confidence. In the present study, this sphere is examined in relation to close relationships, such as those with family or friends. Since illness and pain are bodily expe-

¹⁹ Honneth (1995, 76–77) draws on Mead’s distinction between “I” and “me” to develop the idea of a practical self-relation. Mead sees the “me” as the cognitive self-image a person forms by adopting a second-person perspective on themselves. As children develop basic moral judgments and start evaluating their behavior as “good” or “bad,” their sense of “me” expands to include normative expectations and responses from their social environment, or their “normative action-context.” As their social circles grow, the “me” becomes a practical self-image that evolves through gradual generalization. According to Honneth (1995, 77), “By putting itself in the normative point of view of its interaction partner, the other subject takes over the partner’s moral values and applies them to its practical relation to itself.” Mead’s description of the social self is compatible with feminist critiques of traditional Western ideas of selfhood, which often depict the self as an isolated, rational entity. For example, Alcoff (2006, 89) notes that Mead’s views align with the phenomenological and hermeneutical accounts of the self she supports. Alcoff (2006, 117) also connects Mead’s perspective to Hegel’s, stating, “Since Hegel, one of the most powerful and influential accounts of the self’s dependence on the other was developed by the social psychologist George Herbert Mead. (...) Mead’s formulation takes up Hegel’s belief that the self develops in the context of its relationship with other selves, but Mead turns Hegel’s philosophical speculations into a more empirically based social psychology.” Regarding the concept of self-relation, Honneth (2003a, 138, 192) also references Ernst Tugendhat (1989).

²⁰ Honneth (2003a, 138) links modern society and the present recognition order to the emergence of bourgeois-capitalist society.

riences that significantly affect our physical and emotional well-being, experiencing care or neglect becomes a highly relevant aspect of recognition in the context of endo.

(2) *Respect* concerns the legal sphere, the state, and our capacity for autonomous moral actions. By being granted equal rights to other members of society, including voting rights and access to democratic participation, individuals can develop *self-respect*. Disrespect in this context manifests through the denial of rights or exclusion, which can harm our self-respect. Honneth links this domain to the development of universal human rights. I specifically connect it to Article 25 of the Universal Declaration of Human Rights, which affirms the right to health, well-being, and medical care (United Nations 1948). Although the interviewees might not explicitly mention the Declaration of Human Rights, they implicitly accept the universal right to health and expect equal treatment when seeking medical diagnoses and care. Additionally, I associate legal respect with other forms of state recognition, such as the establishment of national guidelines for endometriosis care (National Board of Health and Welfare 2018). Several interviewees refer to these guidelines and the Swedish welfare state as intended to ensure a certain standard of medical care. According to the interviewees, when these expectations are not met, they may feel abandoned or mistreated by the state.

(3) *Esteem* relates to the communal or solidarity sphere and involves recognition of our concrete traits and abilities as individuals who contribute meaningfully to our community. Social esteem is rooted in our particularities and contributions, and is often linked to what is seen as prestigious within specific “value-horizons” or “styles of life,” and it forms the basis of *self-esteem*. Disrespect in this context includes denigration or insults that target our way of life and threaten our sense of dignity. I mainly associate this area with the stigma surrounding menstruation and the devaluation of “women’s” illnesses, as well as societal ideals of productivity and achievements related to education and work, which can be especially hard to meet due to illness; both of these factors can undermine a person’s self-esteem.

In short, we develop *self-confidence* by being loved and cared for; acquire *self-respect* through equal rights and legal status; and gain *self-esteem* by being valued for our unique traits and contributions to the community. These same core ideas can be expressed using Ikäheimo’s (2022) vocabulary, which expands on Honneth’s framework. Here, love is associated with happiness and well-being (the axiological dimension), respect concerns our co-authority over norms or terms of shared life (the deontological dimension), and esteem relates to our valued contributions to society (the contributive dimension). Ikäheimo’s ideas can be summarized as recognition related to our needs, norms, and contributions.

I see these forms of recognition as occurring in everyday interactions where gender norms and values are also expressed and negotiated. Over time, norms and habits of recognition become institutionalized in society, forming its “recognition order,”²¹ or what Hegel ([1807] 1977, [1821] 1991) calls its “ethical life” (*Sittlichkeit*). Using this framework and drawing on the interview narratives, I identify and analyze how gender dynamics both shape and are shaped by the recognition order surrounding endo. By exploring how others recognize the interviewees and their experiences, we can gain a deeper understanding of the gendered nature of recognition and its impact on the interviewees’ motivations for societal change. I view Honneth’s framework of love, respect, and esteem as valuable tools for analyzing core aspects of what constitutes a “livable life,” which Butler (2009) connects to conditions of “recognizability.” Gender relations greatly influence who is deemed deserving of love, respect, and esteem, and the ways recognition is granted in turn shape gender dynamics. Like Honneth, Butler (2009, 20) emphasizes that the ultimate goal of politics is to secure “the social conditions of persistence and flourishing.” The three forms of recognition help clarify what these conditions involve. Taken together, they provide a framework for analyzing how gender relations shape the recognition of endometriosis.

Applying Hegel’s idea of recognition is not a new approach to the study of gender, which might seem paradoxical since Hegel himself is hardly known as an advocate of gender equality. Nonetheless, revisiting Hegel is relevant to this study for several reasons. First, he is the originator of the philosophy that later recognition theory expands on, with Honneth adhering to many of Hegel’s original ideas. Second, Hegel’s account of recognition has influenced feminist theories of gender through key figures such as Beauvoir and Butler. While the Honnethian and feminist interpretations share similarities, they also differ in their treatment of recognition. It is therefore relevant to review how Hegel has previously been used in gender studies and to consider what Honneth’s interpretation might add beyond what has already been incorporated. Moreover, Honneth has engaged in several debates with leading feminist scholars who sometimes criticize his work. These exchanges offer important insights into his perspective on recognition and inform my own approach to examining how gendered dynamics and recognition shape experiences of illness. I therefore turn to these discussions, beginning with feminist engagements with Hegel.

²¹ Honneth (2003b, 50) describes the “recognition order” as the epoch-specific grammar of social justice and injustice. This includes how feelings of social injustice are shaped by public discourse but also deeper moral principles that determine the linguistic horizon of socio-moral thoughts and feelings in a particular society.

Hegel for Gender Studies

The influence of Hegel and his concept of recognition on gender studies may not be immediately apparent, but it has been significant since its inception, often in indirect ways. A notable example is Simone de Beauvoir's exploration of woman as "the Other," a concept deeply rooted in Hegel's philosophy. Hegel's influence is evident throughout Beauvoir's diaries, autobiographical writings, and her two most well-known philosophical works, *The Second Sex* ([1949] 1956) and *The Ethics of Ambiguity* (1976), where he is frequently referenced.²² Similarly, Judith Butler's work has been significantly influenced by Hegel's ideas, starting with *Subjects of Desire* (1987), a book that explores desire, recognition, and the French reception of Hegel based on Butler's dissertation. In *Bodies That Matter*, referring to Jacques Lacan, who often cited Hegel,²³ Butler reflects on the links between discourse, identification, and recognition, describing misrecognition as "this uneasy sense of standing under a sign to which one does and does not belong" (Butler 1993, 166). This influence is also reflected in Butler's innovative concepts of "frames of recognition" and "recognizability" in *Frames of War* (2009), which I engage with in my discussions of "endo time" and "endo politics."²⁴

Below, I reconstruct a line of influence that starts with Hegel and moves through Beauvoir and Butler. I use the term *reconstruct* deliberately, as this reflects only one possible way of telling the story. As Clare Hemmings (2011, 13) observes, the stories we tell about the past are always motivated by our current position. My goal is not merely historical. Rather, it is to harness key Hegelian ideas related to recognition that are particularly useful for gender studies and for analyzing endometriosis. These ideas can be summarized as three closely connected themes: the notion of "the Other," the processual becoming of subjectivity, and the significance of intersubjective recognition. Beauvoir and Butler serve as central figures in this reconstruction. However, I begin by situating their work within broader feminist engagements with Hegel.

²² Hutchings (2017) finds that Beauvoir primarily refers to Hegel's *Phenomenology of Spirit*, but also to his philosophies of nature, right, and world history (Hegel, 1977, 1837/1980, 1821/1991, 1817/2015).

²³ It may be more accurate to say "Kojève-Hegel," as David Macey does, to reflect that Lacan's understanding of Hegel is significantly filtered through Kojève, whose renowned Hegel lectures Lacan attended (Macey 1988).

²⁴ Butler refers to Hegel several times in the book. For instance, regarding their social ontology, Butler describes how the "shared condition of precariousness implies that the body is constitutively social and interdependent – a view clearly confirmed in different ways by both Hobbes and Hegel" (Butler 2009, 31). In another example, Butler (2009, 142) refers to the Hegelian dialectic of subject formation, stating, "this subject gains its specificity by defining itself against what is outside itself, and so the external differentiation proves to be central to the account of internal differentiation as well. One need go no further than Hegel to make such points."

Emphasizing Hegel's relevance to gender studies may seem counterintuitive, since he was not a feminist.²⁵ Seyla Benhabib once questioned whether the Hegelian dialectic stopped at women, effectively condemning them "to an ahistorical mode of existence, outside the realm of struggle" (Benhabib 1992, 244).²⁶ Kimberly Hutchings, in her book *Hegel and Feminist Philosophy* (2003), points out that Hegel consistently associated women with passivity and particularity (Hutchings 2003, 51, 150). Hegel regarded women as passive in both nature and reproduction, comparing them to plants and considering them unfit for the higher sciences and philosophy (Hegel [1821] 1991, 206–7).²⁷ He also saw women as passive in society, arguing that they belonged to the private sphere, while the "active" domains of civil society and the state were merely mediated through the male head of the household. Additionally, Hegel linked women with particularity, stressing their ethical focus on family, nurturing, and preserving specific individuals. He even referred to womankind as the "internal enemy" and "everlasting irony" in community life (Hegel [1807] 1977, 288), because community depends on dissolving individual ends into universal ends, while women's focus on the particular "perverts" these ends into private ones. As a result, women and the private sphere pose a challenge to the presumed neutrality and universality of the legal sphere (Hutchings 2003, 108). The figure of Antigone, to which I will soon return, exemplifies this challenge for Hegel.

Despite Hegel's views on women, his work has been adapted for feminist purposes, and his influence on feminist philosophy has been extensively discussed (Altman 2007; Dryden 2013; Hutchings 2003; Hutchings and Pulkkinen 2010a; P. J. Mills 1996). Benhabib (1992, 242–43) identifies three feminist responses to Hegel and the Western philosophy tradition more broadly: the teach-

²⁵ For discussions on Hegel, race, and racism, see Christian M. Neugebauer (1990), Sandra Bonetto (2006), and Kimberly Ann Harris and Daniel James (2026).

²⁶ It is worth noting, as Benhabib does, that Hegel was aware of social, cultural, and historical variations in gender relations. Hegel provides examples of men in Egypt wearing "dresses" and remaining at home to weave, while women worked outside and urinated standing up. His remarks on Chinese concubines also present the practice as culturally and socially defined rather than rooted in nature. However, according to Benhabib, Hegel made it clear that he considered one particular family structure and division of labor rational and normatively right: the monogamous sexual practice of the European nuclear family (Benhabib 1992, 246).

²⁷ Hegel states, "Women may well be educated, but they are not made for the higher sciences, for philosophy and certain artistic productions which require a universal element. Women may have insights [*Einfälle*], taste and delicacy, but do not possess the ideal. The difference between man and woman is the difference between animal and plant; the animal is closer in character to man, the plant to woman, for the latter is a more peaceful [process of] unfolding whose principle is the more indeterminate unity of feeling [*Empfindung*]. When women are in charge of the government, the state is in danger, for their actions are based not on the demands of universality but on contingent inclination and opinion" (Hegel [1821] 1991, 207).

ing of the good father, the cry of the rebellious daughter, and the feminist discourse of empowerment. The “good father” reading aligns with mainstream liberal feminism, challenging traditional philosophical views on women but viewing their exclusion as the unfortunate result of historical bias. It seeks to include women within the same Enlightenment framework to correct these exclusions. In contrast, the “rebellious daughter” reading questions inherent binary oppositions, inspired by Lacan’s idea of language as a symbolic universe shaped by the “law of the father,” aiming to reveal “female speech at the margins of the Western logocentric tradition” (Benhabib 1992, 243). Benhabib favors the “feminist discourse of empowerment,” which, like the rebellious daughter, acknowledges gendered subtexts in classical texts without rejecting them outright. It explores categories and ideas from the standpoint of the victims, focusing on women’s actual subjectivity, lives, and activities, serving as an immanent critique. Rather than aligning with any single approach, I maintain that each perspective contributes a vital element to the overall picture.

Hutchings (2003, 3, 12–17, 50–54) introduces a second classification of feminist readings of Hegel comprising four ideal types: the rationalist, critical, sexual difference, and postmodernist approaches. The “rationalist” correlates with Benhabib’s “good father” perspective. The “critical” emphasizes the interdependence between rationality, reason, and interests, drawing from left-Hegelian Marxist thought and critical theory, often referencing the master-slave dialectic. The “sexual difference” approach aligns with Benhabib’s “rebellious daughter,” exemplified by Luce Irigaray, who places sexual difference at the center of deconstructive readings. The “postmodern” approach aims to destabilize the authority within Hegel’s texts, often depicting him as a closed, totalizing thinker, while also noting similarities between his dialectic and deconstruction practices. Hutchings (2003, 52, 81) suggests that Beauvoir fits into the critical approach, while Butler exemplifies the postmodernist approach. Notably, all these approaches, except the good father/rational reading, challenge constitutive categories or binaries. This challenge also has significance for recognition, as seen in Butler’s work, which I will discuss shortly.

Alongside Tuija Pulkkinen, Hutchings (2010b) introduces a third classification of Hegel interpretations: the closed, open, and deconstructive approaches. A “closed” reading assumes Hegel’s writing has a fixed, determinate meaning. An “open” reading sees various interpretations as valuable and productive. A “deconstructive” reading challenges the apparent closure in Hegel’s work from within, using his ideas to oppose the view of him as a philosopher of closure, as seen in Catherine Malabou’s work (Hutchings and Pulkkinen 2010b, 3–4; Malabou 2005). Pulkkinen and Hutchings argue that a closed approach offers limited benefits for feminists, particularly given Hegel’s views on women, while open

and deconstructive approaches have been vital to feminist philosophy. They especially highlight Beauvoir and Irigaray as key feminist thinkers engaging with Hegel: Beauvoir as an open reader who challenges Hegel from within, and Irigaray as a deconstructive reader (Hutchings and Pulkkinen 2010b, 5).

In the following, I focus primarily on Beauvoir and Butler due to their importance for gender studies and their appropriation of Hegelian themes to theorize gender. Although their works differ and draw on various philosophical traditions, I concentrate here on their shared aspects. Two key themes from Hegel's work are often featured in feminist discussions: the struggle for recognition and Hegel's use of the Greek play *Antigone*. Hutchings (2003, 52) suggests that the struggle for recognition often comes to represent the "good Hegel," while his interpretation of *Antigone* stands for the "bad Hegel" that many feminists wish to dispute. Hutchings (2003, 3–4, 81) primarily associates Beauvoir with the struggle for recognition, while Butler is more closely associated with *Antigone*. However, as already mentioned, Butler has a long history of exploring the theme of recognition, and Hutchings' book predates *Frames of War* (2009), where Butler uses the notions of "frames of recognition" and "recognizability." It is reasonable to say that this theme holds significant importance for Butler as well.

Beauvoir: From the Struggle for Recognition to Woman as "Other"

Let us take a closer look at the first theme, representing the "good Hegel." The master-slave dialectic, covered in "Independence and dependence of self-consciousness: Lordship and Bondage," plays a crucial role in Hegel's discussion of recognition and the relational emergence of self-consciousness. This well-known passage from Hegel's *Phenomenology of Spirit* ([1807] 1977), which spans only nine pages, has introduced the ideas of "the other" and "the struggle for recognition" to numerous readers.

In essence, the *Phenomenology of Spirit*, which Butler (1987, 17) describes as a *Bildungsroman*, explores how humanity acquires knowledge about the world and itself. The term "Spirit" is a peculiar concept that Hegel uses to represent human self-consciousness at both individual and collective levels. He characterizes Spirit as an "'I' that is 'We' and 'We' that is 'I'" (Hegel [1807] 1977, 110). This formulation illustrates Hegel's relational view of the subject, which guides the understanding of recognition in my study. According to Hegel, we become who we are through our concrete experiences and relations to others, and we develop self-consciousness by taking ourselves as objects of reflection. Through interactions with others, we learn to adopt an outside perspective on ourselves.

Spirit's journey toward knowledge begins with life and desire – the desire to consume and transform nature for survival. Self-consciousness starts to emerge from the realization that desire has a source: an “I” that desires, along with an identification with this source. However, this desire alone is insufficient to achieve self-consciousness; self-consciousness emerges only through recognition by another being capable of reflecting one's own capacity for it. What Butler (1987, 17) refers to as a *Bildungsroman*, Hutchings (2003, 74) describes as a fable, in which Hegel illustrates how self-consciousness relies on mediation with both nature and other self-conscious beings.

The famous scene that follows illustrates Hegel's dialectics as a struggle for life and death, in which one person seeks to master the other to gain their recognition, only to discover that the self-consciousness of both depends on mutual recognition. The master cannot gain true recognition from the slave if the slave is coerced; such recognition would be meaningless. For recognition to matter, the slave must be recognized as another self-conscious being. The movement of recognition constitutes them both: “Each is for the other the middle term (...) They *recognize* themselves as *mutually recognizing* one another” (Hegel [1807] 1977, 112). The master-slave dialectic shows that understanding ourselves involves realizing that we are driven by both desire and the desire for recognition. This means that we cannot know ourselves in isolation; otherness is essential to this process. Our independence as self-conscious beings depends on others who are also self-conscious. This social aspect reveals a paradox: independence and freedom depend on other people. Hegel famously described freedom as “being with oneself in the other,” a notion Honneth refers to as Hegel's intersubjective structure of freedom (Honneth 2014c, 60).²⁸ Beauvoir echoes this connection between freedom and mutual recognition in *Ethics of Ambiguity* (1976, 73), stating, “To will oneself free is also to will others free.” She later acknowledged that her mode of argument in the book, which uses an immanent critique of different ethical consciousnesses, was modeled on Hegel (Hutchings 2017, 191).

The master-slave dialectic came to play a crucial role in Beauvoir's analysis in *The Second Sex*, where she assigns women the role of the perpetual “Other.” Beauvoir ([1949] 1956, 15–16) effectively uses this idea to establish a man-woman dialectic, concluding that “humanity is male and man defines woman not in herself but as relative to him (...) He is the Subject, he is the Absolute – she is the Other.” Although Beauvoir is primarily known for her use of the concept of the

²⁸ Honneth further proposes that the master-slave dialectic can be understood as Hegel's adaptation of Thomas Hobbes' (2017) notion of the state of nature, describing a hypothetical condition among humans if political institutions that govern social life were to disappear (Honneth 1995, 9–10).

Other, she also integrates Hegel's idea of the movement of recognition as a driving force behind this process of Othering. Hutchings (2003, 70) succinctly summarizes this by stating, "In seeing the master/slave dialectic as central to understanding how women have come to be as they are, Beauvoir (...) puts intersubjective recognition at the heart of both oppression and liberation."²⁹

By using the concept of the Other, Beauvoir elucidates women's oppression and its impact on the formation of a specific gendered subjectivity. She further explores how the process of Othering has influenced the epistemic landscape surrounding women. Noting that women have been deemed inferior in science, philosophy, literature, theology, and other fields, Beauvoir ([1949] 2011, 30–31) cites Poulain de la Barre, who cautions, "Everything that men have written about women should be viewed with suspicion because they are both judge and party." Although my interviews with endometriosis patients took place at a different time and place than the one discussed by Beauvoir, the relationship between knower and knowledge emerged as a significant issue affecting their diagnostic journeys. I explore this topic further in relation to the notion of "endo episteme," focusing on the lived epistemic practices involved in the journey toward knowledge about endo. While these experiences could be interpreted as shaped by a process of Othering, I find that the concept of recognition enables a more detailed description and analysis.

Another important concept that Beauvoir ([1949] 1956, 273) uses to understand gendered subjectivity is the idea of becoming, famously expressed in the statement, "One is not born, but rather becomes, a woman." In my discussion of "endo time," I explore how this notion not only frames Beauvoir's perspective but also Husserl's ([1905] 1991) phenomenological understanding of time, tracing its philosophical origins back to Heraclitus. The concept of becoming is equally vital to Hegel's dialectical framework. Hutchings (2017, 192) observes that Beauvoir's interpretation of what it means to be/become a woman reflects Hegel's description of the development of self-consciousness, such that: "the whole text could be read as a rewriting of the *Phenomenology of Spirit* from women's perspective."³⁰ Hutchings elaborates on this conclusion by outlining the stages that Beauvoir describes, from woman's self-consciousness as a species-being,

²⁹ For further discussions of Hegel's influence on Beauvoir, particularly regarding recognition and the Other, see also Manon Garcia (2025) and Anna Cornelia Ploug (Forthcoming, 2024).

³⁰ Hutchings (2017, 192) writes: "The whole text could be read as a rewriting of the *Phenomenology of Spirit* from woman's perspective, from the emergence of woman's self-conscious being in relation to her natural condition (species), through the different kinds of self-realization available to woman in different historical stages and cultural conditions, culminating in an absolute knowledge in which mutual recognition between men and women becomes possible in modernity."

through the self-realization available at various historical stages, to the mutual recognition possible between the sexes in modernity.

Butler: From Performativity to Recognizability

Almost 40 years later, Butler (1986) built on Beauvoir's insights by arguing that Beauvoir's groundbreaking statement on becoming woman effectively distinguishes sex from gender. This distinction, according to Butler, frames gender as an aspect of identity that is gradually acquired over time and has been vital for feminist efforts to separate anatomy from destiny and social function from biological necessity. While sex refers to "the factic aspects of the female body," gender describes "the cultural meaning and form that that body acquires" (Butler 1986, 35). In this early work, Butler incorporates several phenomenological elements into the conceptualization of gender performativity (Butler 1988; Käll 2014). In the landmark text *Gender Trouble* (1990), which brought the idea of gender performativity to a broader audience, Butler details how gender is constructed and perpetuated through stylized repetitions of acts. In this book, Butler (1990, 43) expands upon and elaborates on Beauvoir's ideas about gendered becoming, characterizing it as a discursive practice:

If there is something right in Beauvoir's claim that one is not born, but rather *becomes* a woman, it follows that *woman* itself is a term in process, a becoming, a constructing that cannot rightfully be said to originate or to end. As an ongoing discursive practice, it is open to intervention and resignification.

Butler's concept of gender performativity, along with what later became known as queer theory, has been seminal in forming gender studies as an academic field. However, critics have argued that Butler's idea of performativity presents sex/gender in overly voluntaristic terms (Käll 2015). Butler responds to such criticism in *Bodies That Matter* (1993) and further develops the notion of performativity. Here, Butler underscores a processual logic, not unlike the Hegelian master-slave dialectic, where self-consciousness is constituted not by isolated individuals but through a process of interactions over time (Butler 1993, 60):

[P]erformativity cannot be understood outside of a process of iterability, a regularized and constrained repetition of norms. And this repetition is not performed *by* a subject; this repetition is what enables a subject and constitutes the temporal condition for the subject.

This processual logic resonates with my understanding of subject formation and aligns well with the concept of recognition. However, in comparison to the concept of performativity, recognition provides a more suitable framework for this study. It emphasizes the importance of experience, social interaction, and what it means to be the recipient of acts of recognition. It further details how different forms of recognition matter for our self-relation and inspire struggles for change.

Hegelian themes also appear in Butler's *Undoing Gender* (2004b). While the master-slave dialectic is famous for illustrating Hegel's discussion of recognition, this concept extends well beyond that scenario. Recognition also plays a crucial role in Hegel's conception of love ([1821] 1991, 199):

The first moment in love is that I do not wish to be an independent person in my own right [*für mich*] and that, if I were, I would feel deficient and incomplete. The second moment is that I find myself in another person, that I gain recognition in this person [*daß ich in ihr gelte*], who in turn gains recognition in me. Love is therefore the most immense contradiction; the understanding cannot resolve it, because there is nothing more intractable than this punctiliousness of the self-consciousness which is negated and which I ought nevertheless to possess as affirmative. Love is both the production and resolution of this contradiction.

Butler (2004a, 23) echoes Hegel's "contradiction" by emphasizing that we are not just constituted but "undone" by one another: "Let's face it. We're undone by each other. And if we're not, we're missing something. This seems so clearly the case with grief, but it can be so only because it was already the case with desire." These reflections sharply contrast with the notion that recognition primarily revolves around the struggle for life and death. It is our social nature and the interconnection between self and Other that expose us to the risk of misrecognition. Our social nature and vulnerability to recognition and misrecognition harbor the possibility of both affirmation and denial from others, spanning love and destruction.

Importantly, while I draw these parallels to Hegel, I do not suggest that he is the primary influence; Butler engages extensively with thinkers like Michel Foucault, Freud, Lacan, Jacques Derrida, Irigaray, and Plato. Additionally, Butler (1993, 76) often critiques Hegel, arguing that, unlike Hegel's views, "the subject cannot reflect on the entire process of its formation." Butler (1993, 77) also links "appropriating all difference into unity" to a "Hegelian synthesis which has no exterior." Similarly, Beauvoir rejects Hegelian absolutism and "rationalistic optimism" (Hutchings 2017). Thus, suggesting a Hegelian influence in Butler and Beauvoir does not imply full endorsement. This critical engagement with Hegel becomes even more evident in Butler's discussion of the "bad Hegel," the Hegel who writes about *Antigone*.

Let us now turn to *Antigone*, a tragedy by Sophocles, first performed around 441 B.C. The play tells the story of Antigone, who is determined to give her brother Polyneices a proper burial. This act of defiance goes against her uncle Creon, the new ruler of Thebes, who has declared Polyneices an enemy of the state and forbidden his burial. Antigone's act of rebellion prioritizes her family bonds and obligation to her brother over Creon's laws of the city. While Hegel's master-slave dialectic does not address gender, his references to *Antigone* appear alongside his discussion of the role of women, associating them with the family sphere. Hegel uses the figure of Antigone to explore the role of women and what he refers to as the tragic constitution of the pagan world. He presents a historical scenario in which men first enter universality as citizens, thereby creating a conflict between the ethics of the family and those of the state.

Hegel's interpretation has sparked extensive feminist discussion, with many interpreting Antigone as a symbol of rebellion against male domination while simultaneously critiquing Hegel's reading of the play.³¹ Patricia J. Mills suggests that Antigone serves as a paradigmatic figure for Hegel, crucial to understanding his view of women. According to Mills (1986, 133), Hegel sees in Antigone that "the conflict between family and *polis*, particular and universal, is also the conflict between man and woman. Nature, according to Hegel, assigns woman to divine law and man to human law." Mills contends that Hegel overlooks the significance of Antigone's actions, noting that she transcends her expected familial role and enters the *polis* by risking her life, similar to men. Antigone's rebellion results in her being buried alive, making her a paradoxical figure of the typical female role – something Hegel fails to see.

Butler's analysis of *Antigone* similarly challenges Hegel's interpretation. In *Antigone's Claim*, Butler (2000, 1) highlights how Antigone is often seen as a symbol of feminist resistance, representing "a principle of feminine defiance of statism and an example of anti-authoritarianism." This view contrasts sharply with Hegel's portrayal of Antigone as linked to kinship and a "prepolitical opposition to politics" (Butler 2000, 2). Contra Hegel, Butler argues that *Antigone* actively challenges prevailing norms of both gender and kinship, suggesting that the play can be read as an allegory for the limits of intelligibility, where only certain forms of kinship, love, and mourning are recognized. In this light, Butler notes that the play anticipates publicly ungrievable losses, such as those related to AIDS. Additionally, Butler underscores the role of recognition in shaping Antigone's situation. Although Antigone cannot attain recognition from the state in terms of

³¹ See for example Irigaray's discussions of Antigone (1985a, 2010), and *Feminist Readings of Antigone* (Söderbäck 2010), which contains texts by Judith Butler, Adriana Cavarero, Julia Kristeva, and Fanny Söderbäck, among others.

citizenship, her commitment to her brother situates her within the sphere of kinship (Butler 2000, 13).

Although Hegel fails to see Antigone as a political figure, his interpretation offers an interesting perspective, particularly his view that the play demonstrates a conflict between the ethical obligations underpinning two distinct societal spheres: the family and the state. This clash drives Antigone's defiance against Creon, who represents the state's powerful authority. According to Butler, by contrasting Antigone with Creon and the family with the state, Hegel fails to recognize the extent to which Antigone diverges from traditional family norms. Butler highlights the irony in Hegel's depiction of Antigone as a normative representative of kinship, especially given her incestuous background as Oedipus's daughter. One could say that Butler "queers" the kinship in *Antigone* by emphasizing Antigone's obsession with her brother, her assertive "manly" actions, and the fact that Creon, who derives his authority from blood ties, is rendered "unmanly" in the face of Antigone's rebellion. Butler's critique of Hegel's clear division between the family and the state reflects a feminist criticism sometimes leveled against recognition theory, which I will return to. This criticism questions the separation of distinct societal spheres of recognition, which Hegel ([1821] 1991, 62) defines as the family, civil society, and the state.

Butler's engagement with *Antigone* demonstrates how Hegel's ideas can also be used to critique Hegel. While Butler highlights the importance of recognition, Hegel seems unable to view Antigone's rebellion as a struggle for recognition. As Butler and others note, Antigone remains a powerful metaphor for feminist struggles, resonating with this study's interviewees who similarly seek state recognition. Their advocacy for national guidelines for endometriosis care is a call for public recognition of a condition often regarded as a private matter. Menstrual stigma tends to portray endometriosis as a "private" issue rather than a "public" concern, which makes discussions about endometriosis more difficult and leads to the privatization of symptoms. Antigone's symbolism gains greater significance when considering the role of menstruation in endometriosis and Butler's suggestion that Antigone represents not only blood relations but blood itself. Drawing on Irigaray, Butler describes blood as a bodily and graphic element that politics cannot fully encompass. As Butler (2000, 4) states, "by signifying 'blood,' Antigone does not precisely signify a blood line but something more like 'bloodshed' – that which must be remaindered for authoritarian states to be maintained. The feminine, as it were, becomes this remainder." The historical link between women, blood, and the private sphere continues to pose a challenge to public recognition, a barrier the interviewees seek to overcome. In analyzing "endo politics," I explore how the interviewees transform their individual experiences into

collective action, enacting the feminist principle that the personal is political. Using Hegel's concept of recognition to address gender dynamics in this way, and as Butler does with *Antigone*, makes it possible to work both with and against Hegel simultaneously.

Throughout Butler's analysis of *Antigone*, several themes emerge that resonate with their later discussions of recognition. These themes include the connection between recognition and intelligibility, as well as how this relationship influences which lives are deemed grievable. Butler further explores these ideas in *Frames of War* (2009), subtitled "When is Life Grievable?" In this work, the concepts of "frames of recognition" and "recognizability" are developed.³² Butler (2009, 5) defines recognizability as follows:

If recognition characterizes an act or a practice or even a scene between subjects, then 'recognizability' characterizes the more general conditions that prepare or shape a subject for recognition (...). These categories, conventions, and norms that prepare or establish a subject for recognition, that induce a subject of this kind, precede and make possible the act of recognition itself. In this sense, recognizability precedes recognition.

For Butler, recognizability signifies the historical conditions that lay the groundwork for recognition. Referring to Hegel and accepting his basic premise, Butler further elaborates on the connection between recognizability and intelligibility (Butler 2009, 6):

If recognition is an act or practice undertaken by at least two subjects, and which, as the Hegelian frame would suggest, constitutes a reciprocal action, then recognizability describes those general conditions on the basis of which recognition can and does take place. It seems, then, that there are still two further terms to understand: *apprehension*, understood as a mode of knowing that is yet not recognition, or may remain irreducible to recognition; and *intelligibility*, understood as the general historical schema or schemas that establish domains of the knowable.

Intelligibility thus describes the historical schemas that establish what is "knowable." Butler also emphasizes that recognizability is not an inherent quality of individual humans. Instead, there are "frames of recognition" that generate specific ontologies of the subject, shaping how subjects are understood and recognized. These frames are subject to change, meaning that they are both constitutive of and constituted by the subjects themselves.

³² Butler uses the term "recognizability" in *Undoing Gender* (Butler 2004b, 9, 10, 109, 112, 114) but develops the notion further in *Frames of War*.

Butler's notion of recognizability as preceding recognition is significant, as it highlights how categories, norms, and schemas of intelligibility prepare subjects for recognition. This perspective can help clarify how the cultural framing of endometriosis as a "women's disease" impacts the recognition of those affected. However, Butler does not elaborate on the concept of recognition itself with the same level of detail, which supposedly comes *after* recognizability. Butler has recently discussed the meaning of recognition with Honneth in the book *Recognition and Ambivalence* (Ikäheimo et al. 2021) and has also criticized Honneth for not fully appreciating the ambivalence of recognition, which I will return to.

Ultimately, Butler suggests that the relationship between Antigone and Creon is not one of simple opposition. Instead, they form a chiasmic relationship, reflecting each other in ways that resist clear separation. Butler (2000, 4) describes them as "metaphorically implicated in one another." Although Butler critiques Hegel's interpretation, this depiction of their chiasmic connection also mirrors a Hegelian dialectic, in which the parties are mutually constitutive. Interestingly, even critiques of Hegel often employ the analytical tools he promoted. Foucault, for example, has noted the difficulty of fully escaping Hegel's influence. While he frequently criticizes Hegel – calling his dialectic "a way of evading the always open and hazardous reality of conflict by reducing it to a Hegelian skeleton"³³ – Foucault (1971, 28) also acknowledges his lasting influence:

[T]ruly to escape Hegel involves an exact appreciation of the price we have to pay to detach ourselves from him. It assumes that we are aware of the extent to which Hegel, insidiously perhaps, is close to us; it implies a knowledge, in that which permits us to think against Hegel, of that which remains Hegelian. We have to determine the extent to which our anti-Hegelianism is possibly one of his tricks directed against us, at the end of which he stands, motionless, waiting for us.

This influence also played a role in the emergence of gender studies. Historically, the field has depended heavily on the distinction between sex and gender – a distinction that Butler identifies in Beauvoir's work, even though Beauvoir herself did not use these specific terms. Furthermore, it is hard to envision the evolution of gender studies without Butler's reinterpretation of these ideas into the concept of gender performativity, which was crucial for the development of queer theory.

³³ From Foucault (1980, 114–15). It is also worth noting that Foucault's relationship with Hegel began at an early stage. In 1949, he earned his *diplôme d'études supérieures*, equivalent today of a master's degree, under the guidance of Hegel expert Jean Hyppolite. Foucault's thesis explored Hegel's *Phenomenology of Spirit*, drawing on Husserl's genetic phenomenology (Roberts-Garratt 2024).

A Complicated Line of Influence: A Productive Paradox

I have reconstructed a line of influence that begins with Hegel and moves through Beauvoir and Butler. This trajectory highlights several key ideas central to my analysis: “the Other,” the processual becoming of subjectivity, and the significance of intersubjective recognition. Understanding gendered becoming as shaped by recognition processes thus involves following both Beauvoir’s and Butler’s paths, despite the significant differences between their approaches.

In this respect, I suggest that gender studies could benefit from revisiting Hegel, much as Axel Honneth sought to reconnect critical theory with its left-Hegelian roots. Returning to Hegel’s concept of recognition – and its further evolution in later recognition theory – offers a productive way of illuminating gender dynamics. In particular, it allows us to reconsider how recognition takes different forms and operates across distinct spheres of social life.

Although Butler refers to the family and the state in their discussion of Antigone, neither Butler nor Beauvoir applies Hegel’s multidimensional understanding of recognition, later elaborated by Honneth, as an explicit analytical tool. Revisiting this Hegelian perspective is particularly relevant for analyzing endometriosis in two respects. First, endometriosis, like any illness, is an embodied experience that unfolds across the different forms and spheres of recognition. Second, endometriosis has sparked a social movement and is increasingly seen as a site of political struggle, exemplifying a contemporary struggle for recognition.

Yet returning to Hegel also raises an obvious difficulty: his own discussions of women appear deeply problematic. But how should we approach Hegel’s views on women? Can his ideas still be productively used in gender studies – and in the study of endometriosis? Hegel’s association of women with the private sphere and men with the public sphere is clearly outdated, and his discussions of gender make little sense. How can women occupy the role of the particular when Hegel’s dialectic of the particular and universal is supposed to drive history? In Hegel’s account, women are somehow portrayed both as outside of and as drivers of history. This tension may seem paradoxical, but it has been productive for feminist thought, as Beauvoir and Butler effectively demonstrate. One can readily think of instances in which women have functioned as “particulars” that challenge supposed “universals,” much like Antigone. Consider, for example, the struggle for recognition of diseases associated with women. In such cases, the male body has frequently functioned as (false) “universal,” while female bodies appear as “particulars” or Others that challenge conventional categories, norms, and medical knowledge.

Hutchings suggests that Beauvoir’s work highlights both the challenges and potential benefits of integrating Hegelian and feminist thought. On the one hand,

Hegelian categories can be subjected to feminist critique; on the other, affinities between his work and feminist theory can also be revealed (Hutchings 2003, 57). I agree with Hutchings that feminists can leverage Hegel to critique his own ideas and expand his concepts beyond their initial intent. Hegel himself emphasizes that knowledge is historically contingent and provisional. As he famously writes, each individual is “a *child of his time*; thus philosophy, too, is *its own time apprehended in thoughts*” (Hegel [1821] 1991, 21). He implicitly acknowledges that his philosophy, too, is shaped by its time and place. Moreover, Hegel’s view that knowledge claims are not universally valid but partial, and need to be shared to persist, provides a foundation for critique (Hutchings 2003, 105–7). His framework allows us to argue that his assertions about women are fragile, collapsing like a house of cards, simply because they are no longer widely shared. Ultimately, this shift reflects a change in how society recognizes women. Hegel’s concept of recognition, consequently, enables us to examine how society recognizes different groups, bodies, or phenomena like endo, and how this recognition can be transformed over time. By closely investigating the processes of recognition, we can also analyze their gendered dimensions, moving beyond Hegel’s own limited perspective.

Beyond Hegel, feminist scholars have also engaged with and critiqued Honneth’s recognition theory. Honneth himself has also taken part in several debates with prominent feminist thinkers. These discussions are helpful for situating my own approach to recognition, and I therefore provide a brief overview of the debates most relevant in this regard.

Honneth and Feminist Debates

Several scholars in feminist theory and philosophy have engaged with Honneth’s recognition theory, emphasizing his view that the feminist movement exemplifies the struggle for recognition and that his theory offers numerous resources for feminist critique (I. M. Young 2007, 193). Christopher F Zurn (1997) was among the first to suggest that Honneth’s recognition spheres could illuminate the moral claims underpinning feminist struggles. Federica Gregoratto (2015) draws on both Honneth and Jessica Benjamin to analyze gender domination as a *pathology of love*. However, as Gregoratto notes, despite recognition becoming a central concept in social and political philosophy, it has not yet significantly influenced debates within feminist, gender, or queer theory.

Recognition and Redistribution: A Unified Framework of Recognition?

In a noteworthy debate with Nancy Fraser, Honneth advocates a unified theoretical framework of recognition that avoids creating an insurmountable theoretical divide between the “material” and “symbolic” aspects of social reality (Honneth 2003a, 112–13). He argues that recognition is inherently linked to redistribution, contrasting this view with Fraser’s two-dimensional perspective on justice, which separates these components.³⁴ Rather than beginning from a distinction between material and symbolic aspects, Honneth considers both of them as outcomes of sociohistorical processes of institutionalization. This comprehensive framework addresses both historical and current struggles for emancipation and challenges the perception that the quest for recognition is a recent phenomenon tied to new social movements that focus on issues like gender, race, ethnicity, and LGBTQ+ rights, often labeled as “identity politics.” While Honneth and Fraser agree on the centrality of redistribution, with Honneth acknowledging that fair distribution of essential goods should be prioritized, he contends that recognition offers a more effective conceptual tool for addressing modern political demands (Honneth 2003a, 112). He asserts that even issues of distributional injustice are always normatively embedded and should be interpreted as institutional expressions of unjust relations of recognition (Honneth 2003a, 114). Young (1997, 154) has similarly criticized Fraser’s dual systems theory for being overly reductive, citing Pierre Bourdieu’s work as illustrating the intricate ways in which “[p]olitical economy is cultural, and culture is economic.”³⁵

A unified framework of recognition resonates with my own understanding. Furthermore, a sharp distinction between “symbolic” and “material” aspects can be especially unhelpful when exploring endometriosis and justice. This can be illustrated by the limited attention that theories of justice often devote to health and illness, in contrast to wealth. Despite the fundamental connection between health and wealth, the former rarely receives the same level of scrutiny. One of the most influential theorists of justice, John Rawls, describes health as a “natural good” that is influenced by luck over the life course rather than being socially

³⁴ Fraser argues that struggles for recognition tend to affirm group differences tied to status and culture, while struggles for redistribution aim to dismantle the economic systems supporting these identities. She cautions that an emphasis on group differences can distract from distribution issues, fostering separatism and conformity instead of deconstructing differences. Fraser believes that recognition struggles are more effective when they focus on equal participation rather than affirming identities, which she terms the “identity model” of recognition (Fraser 2000). Critics, however, contend that her views oversimplify identity and unfairly target movements she already classifies as identity politics (Alcoff 2007), portraying them as “merely cultural” (Butler 1997).

³⁵ See also Beverly Skeggs (2001), who similarly uses Bourdieu’s notion of cultural capital to discuss recognition.

determined (Rawls 1971, 62).³⁶ As a result, within this framework, health falls outside of the scope of justice. Sridhar Venkatapuram (2011) attributes this oversight to a narrow conceptualization of health and a lack of awareness of the significant social factors that shape it. The physical and social environments in which people grow, live, work, and age have a profound impact on health, illness, and longevity (CSDH 2008). Moreover, unjust social conditions not only cause illness but also affect an individual's ability to change these circumstances (Venkatapuram 2011, 9).

Unlike thinkers like Rawls, economist-philosopher Amartya Sen argues that discussions of social justice must address health and illness (Venkatapuram 2011, 2–3). Alongside Martha Nussbaum, Sen has developed the capability approach, which is grounded on the normative assumption that the freedom to achieve well-being depends on what people can actually do and be, as well as the kind of life they can lead (Sen 1980, 1985, 2020; Nussbaum 1988, 1992, 2000; Nussbaum and Sen 1993). This approach places well-being at the forefront of moral considerations and has been influential in welfare economics, development studies, and empirically based political theory (Wolff and de-Shalit 2007).³⁷ However, for my exploration of how gender and recognition shape illness experiences, recognition theory provides a more comprehensive framework than the capabilities approach. Recognition theory emphasizes the significance of intersubjective interactions and their impact on individuals' self-relations and motivations for political change. Honneth's framework offers a nuanced understanding of justice that integrates recognition and redistribution, enriching the discourse on social struggles and emancipation.

Recognition and Gender: Feminist Ethics or Outdated Views on Progress?

Both Young and Lois McNay (2021) note that Honneth stands out among political theorists for consistently addressing love, care work, gender inequality, and the gender division of labor within a broader understanding of justice, in line with feminist ethicists. McNay adds that his method of normative reconstruction parallels feminist critiques of ideal theory in political philosophy. Furthermore,

³⁶ Rawls' notion of social primary goods includes rights and liberties, powers and opportunities, income and wealth, and the bases of self-respect etc. He addresses health and vigor as exceptions to the equal distribution of primary goods. He suggests that health and vigor may be influenced by the basic structure for distribution, but are not directly controlled by it: "Other primary goods such as health and vigor, intelligence and imagination, are natural goods; although their possession is influenced by the basic structure, they are not so directly under its control" (Rawls 1971, 62).

³⁷ The United Nations Development Program (UNDP) has used the capability approach in the Human Development Report published annually since 1990. In recent years, UNDP has also discussed the use of this approach (see UNDP 2016).

Honneth's phenomenology of social experiences of injustice resonates with feminist aims of recovering and revaluing experiences of women that are often overlooked in mainstream theory (McNay 2021). My exploration of "endo" both reflects and builds on this tradition.

Despite these benefits, Young (2007) contends that Honneth's work on recognition related to love and care lacks the specificity needed for effective feminist critique. She argues that he does not sufficiently address the "functional stubbornness" of the gender division of labor, which assigns this type of work to women (I. M. Young 2007, 193). For Young, merely acknowledging care work through the lens of social esteem is insufficient. She suggests softening the boundaries between the spheres of love and esteem to achieve a more comprehensive understanding. Similarly, McNay (2021) argues that Honneth's view of the family as operating around an inner logic of care overlooks the ways in which social and economic logics also penetrate it. Unlike Young's more immanent critique, this leads McNay to question whether a "monistic" theoretical framework based on recognition can adequately address gender inequality. McNay (2015, 2021) also suggests that Honneth's reliance on a Hegelian teleological notion of historical progress might lead him to underestimate negative features, such as the persistence of the gender division of labor and domestic violence (see also Allen 2016).

In my reading, Honneth does not assume strict boundaries between spheres, as Young and McNay suggest. In the earlier discussion with Fraser, he clarifies that he opposes Hegel's "systematic closure," which connects different forms of recognition to specific, bounded institutions. Honneth (2003a, 146) describes it as "self-evident" that institutional complexes involve multiple intertwined forms of recognition, and gives the example of how "the modern 'bourgeois' nuclear family is an institution in which the legal regulation of intrafamilial interaction has gradually complemented the principle of love." Therefore, the spheres are understood at a principles level, analytically located above particular social or legal institutions. This reasoning aligns with my view that love, respect, and esteem can be seen as recognition principles that underpin the interviewees' expectations of recognition. I find this framework helpful for analyzing gender inequality, even though it lacks, as Young puts it, the "specificity needed" for effective feminist critique. My goal is to provide this specificity by analyzing endometriosis experiences. I use the forms of recognition as analytical tools that highlight typical patterns rather than strict boundaries or purity. Instead of viewing the recognition framework as inadequate and "monistic," as McNay suggests, I see it as valuable for understanding illness experiences, because it is both unified – integrating material and symbolic aspects – and multifaceted, reflecting the various forms of recognition involved.

Regarding progress, Honneth (2002, 510) indeed argues that a conception of progress is necessary to counter value relativism. To avoid viewing all changes in recognitive norms as equally good, he links progress to changes that both increase individuality and social inclusion.³⁸ He mentions increased democratization and evolving gender relations, including the “democratization” of intimate relationships, as examples of such changes (Honneth 2014c, 144). I agree that evaluating social change requires some conception of progress, similar to ideas of emancipation or flourishing, but this does not imply that progress is inevitable – if it were, struggles for recognition would be pointless. I also believe that, despite ongoing challenges, Western societies have generally become more gender equal over the last century. Moreover, social struggles are driven by implicit views of what constitutes progress, and evaluating them involves normative judgments about their goals. In the case of endometriosis, I agree with the interviewees that the development of national guidelines for endometriosis care is a meaningful sign of societal progress in managing the condition. Such normative assessment needs to be conducted on a case-by-case basis.

Recognition and Ambivalence: An Optimistic View on Human Nature?

Another notable critique of Honneth’s theory concerns whether he relies on an overly optimistic anthropology, or view of human nature, and inadequately addresses the ambivalence of recognition.

I will highlight the contributions of Butler and Amy Allen, who are especially relevant given their feminist engagements with critical theory. Butler challenges an optimistic view of human nature in response to Honneth’s 2005 Tanner Lectures, *Reification: A New Look at an Old Idea*.³⁹ Butler (2008, 108) states that Honneth’s view of recognition seems to assume that transforming the social relations that cause poor recognition would enable a “‘return’ to a genuine praxis that, luckily, is always lurking just beneath our instrumental attitudes.” Butler argues that this perspective presumes a normative content in human nature and also emphasizes the intricate dependencies involved in forming human bonds. This inevitably generates, according to Butler (2008, 108), a “permanent necessity of aggression, of breaking and separating, on the one hand, and dependency, helplessness, and need, on the other hand.” Butler rhetorically asks, “What human

³⁸ Or, expressed differently: changes that enable “autonomy and self-realization,” which Honneth (2002, 516–17) describes as “being able to freely determine and realize [one’s] desires and intentions (...) free from domination or compulsion.”

³⁹ Raymond Geuss and Jonathan Lear are the two other commentators on Honneth’s Tanner Lectures, and they also address the topic of an optimistic anthropology. These debates are collected in *Reification: A New Look at an Old Idea* (Honneth 2008c).

escapes this struggle between love and aggression?” Butler’s statement can be interpreted as implying that Honneth believes humans *can* escape this struggle and consequently holds an optimistic view of human nature, which colors his account of recognition.

While Butler’s critique is interesting, I see the claims of optimism as misguided. First, Honneth distinguishes normative recognition from an antecedent, “elementary” form of recognition, which involves perceiving others as intentional beings like oneself and underpins intersubjectivity, but lacks a normative orientation. According to Honneth (2008d, 152), “Although it compels us to take up some sort of position, it does not determine the direction or tone of that position. Love and hate, ambivalence and coldness, can all be expressions of this elementary recognition.” Consequently, he does not ascribe a normative content to human nature itself. Instead, the normative aspect arises when recognition is embodied in actual social practices and institutions – when “the existential scheme of experience opened up by elementary recognition gets ‘filled out’ historically” (Honneth 2008d, 152). My analysis of the interviewees’ accounts focuses on these concrete embodiments of recognition.

Second, Butler’s charge of optimism addresses recognition, but in my reading, the key difference between Butler and Honneth lies in their perspectives on human aggression and its implications for human nature. To clarify this, a brief detour into psychoanalytic theory is needed, as Butler (2008, 106) connects the ambivalence of recognition to the ambivalent structure of the psyche, arguing that “psychic reality is, by definition, ambivalent.” Butler’s account of ambivalence is rooted in Freud’s notion of the death drive, further developed in Melanie Klein’s object relations theory, which Butler (2008, 108) sees as underpinning “the permanent necessity of aggression.”⁴⁰ In contrast, Honneth rejects the idea of the death drive based on empirical research, arguing that we lack “empirical observations which allow us to say what content these drives have” (Inara 2009). He points out that most child psychology shows “that aggressive behaviour on the part of small children – primitive expressions of anger and hostility – are to be understood not as endogenous drives, but as a reaction to unpleasant experiences” (Honneth 2014b, 221).⁴¹ Notably, Honneth draws on Winnicott’s object

⁴⁰ For a discussion of Klein’s influence on Butler, see Nyström (2022). Butler (2019) also uses Freud’s notion of the death drive for social critique, as seen in discussions of Donald Trump, while at the same time stating that there is no need “to subscribe to a biological notion of the death drive,” making the exact status of the concept somewhat ambiguous in Butler’s thought.

⁴¹ Honneth (2014b) develops these thoughts in a discussion with Joel Whitebook and in response to claims that the intersubjective turn within critical theory, which Honneth represents, betrays the motif of “negativity” and non-conformism at the heart of the subject. As in Butler, this motif of negativity in early critical theory is rooted in Freud’s death drive, which supposedly embeds an

relations theory rather than Klein's, and Winnicott himself was a staunch critic of the death drive (Picht 2022). Consequently, Butler and Honneth's differing views are linked to distinct psychoanalytic traditions and different opinions on the death drive. Honneth clearly states that both love and hate can flow from the intersubjective encounter, but he does not find support for the idea of inherent aggression linked to the death drive. In my view, rejecting the death drive on empirical grounds does not imply an optimistic view of human nature, and I consider Honneth's integration of empirical research a strength rather than a weakness.⁴²

Relatedly, Amy Allen (2021) finds an optimistic anthropology in Honneth's account of love, which she argues depends on an image of blissful psychological fusion. Allen (2021, 117) argues that this influences Honneth's view on recognition, which she claims is grounded in "a logic of fusion according to which integration and inclusion into social structures and institutions of recognition are understood as unequivocally good, while their lack is seen as unequivocally bad." However, I believe Allen is too quick to draw this conclusion. Although Honneth describes humans as seeking moments of affective fusion in love and other relationships, this does not mean he equates love or recognition with fusion. Additionally, Honneth (2014b, 228) does not claim that fusion is inherently good or bad; he merely indicates that people tend to seek this state, referring to "a constitutive receptivity to experiences of fusion," which is something else. In parallel, my analysis of "endo politics" finds that becoming a "we" with other endometriosis patients is central to the interviewees' experiences, reflecting a common desire for affective unity with others. I see this process of forming a collective identity as a way of seeking alternative communities precisely because they are dissatisfied with current social structures. While Honneth stresses the importance of social integration for social beings, this does not imply that existing social structures are viewed positively. If they were, struggles for recognition would be unnecessary and difficult to defend normatively. Similarly, while Honneth describes a desire for recognition, he does not regard all such struggles as positive. In his debate with Fraser, he gives the following example: "The social movements today demanding recognition of their value convictions include not only peaceful

asocial tendency in the subject and a structural conflict between the individual and the social order. Honneth argues that critique does not have to rely on this specific Freudian tradition.

⁴² Butler criticizes Honneth for relying on empirical research from socialization and developmental psychology, which Butler considers a debated field. Additionally, Butler goes beyond this specific area, challenging the use of empirical studies, asking why we "should accept the results of any such research (...) why the turn to the empirical here at all?" While I agree that not all empirical research should be accepted uncritically, Butler's position seems excessive, likening observational studies to "reification" and thus dismissing such input (see Honneth 2008b).

groups like feminists or marginalised minorities, but also racist and nationalist groups such as Farrakhan’s Nation of Islam and German skinheads” (Honneth 2003a, 121). Honneth’s recognition framework remains useful for this study because it identifies the underlying motivations of recognition struggles, such as those related to endometriosis, without assuming these struggles are inherently good. The normative assessment is left to the social philosopher, supported by the method of normative reconstruction.

Recognition and Recognizability: A Positive Sense of Recognition?

While I do not believe Honneth relies on an optimistic anthropology, it is important to note that the idea of mutual recognition is intended to convey a *positive* meaning. Honneth uses “recognition” in a specific sense, as seen in his debate with Butler in *Recognition and Ambivalence* (Ikäheimo et al. 2021). In this discussion, Honneth (2021b) clarifies that he adopts a Hegelian understanding of recognition, which involves a dyadic relationship with normative implications for both parties. This form of recognition refers to acts that grant a normative status to their recipient and require the giver to limit their own freedom. More specifically, Honneth (2014d, 80) suggests that recognition should be viewed as a practical attitude, or “stance” (*Haltung*), expressed through concrete actions. The three forms of recognition are typical ways recognition appears in society, though rarely in pure or perfect form. On the contrary, this gap motivates groups and individuals to pursue changes in how recognition is organized. Most people want to be loved, respected, and socially esteemed – these are clearly positive notions. While Honneth reserves the term “recognition” for this positive sense, he uses phrases like “recognition order” to describe how recognition is embodied in society.

In response, Butler agrees that Hegel envisioned recognition as a dyadic relation transforming the subjects involved. However, Butler questions whether individuals “grant” recognition to one another, and whether what is granted constitutes a moral value or normative standing. Butler states, “I think that recognition is not a punctual act, and it is not exactly performed by a subject for or on another subject” (2021b, 47). For Butler, recognition is less about concrete acts between individuals and more about social ontology and the discursive conditions of subject formation. Butler introduces the concept of “recognizability” to describe these discursive conditions that precede and prepare a subject for recognition, but does not theorize “recognition” itself. I argue that in Butler’s theorizing, recognizability takes precedence to the point that the concept of “recognition” collapses into “recognizability.” Honneth makes a similar point in their de-

bate. While acknowledging that we are “inescapably categorized by different classificatory schemas that squeeze us into socially standardized types” (Honneth 2021a, 57), he maintains that Hegel’s term refers to something different. While categorization tends to restrict freedom, recognition in Hegel’s sense expands it. Honneth contends that Butler conflates two different ways of treating subjects under the same term. He suggests that by merging two distinct understandings of recognition – one *cognitive*, linked to categorization and intelligibility, and the other *normative*, which he prefers – Butler fails to clearly distinguish the two.

This study, which focuses on first-person experiences, requires a concept of recognition that involves concrete acts between individuals. Although I see recognition as intertwined with socialization, social ascription, and intelligibility, it is vital to have a distinct term to differentiate these notions. Clarifying the positive content of Hegelian recognition – what we desire when we desire recognition – is crucial to avoid using an undertheorized concept. Honneth’s theory is helpful in this regard, as it elucidates what a desire for recognition entails and how it can motivate struggles for change. Such positive concepts are often needed in normative theories to address real-world injustices. Like Honneth, Butler (2009, 20) frequently refers to human “flourishing” as central, a concept they do not describe as similarly marked by ambivalence. Honneth, in turn, identifies love, respect, and esteem as fundamental to achieving human flourishing. I further expand on the differences between Honneth and Butler in my discussion of “endo politics,” concluding that both perspectives are valuable for understanding the interviewees’ experiences and can be combined, but they should not be conflated. While I rely on Honneth’s understanding of “recognition,” I also find Butler’s concept of “recognizability” useful for analyzing discursive frames and conditions, and this concept is more clearly defined in Butler.

Recognition and Power: A Deficit Model of Recognition?

A final debate involves critics arguing that Honneth’s recognition theory obscures the link between power and recognition. Paddy McQueen is relevant here because he discusses this theme in the book *Subjectivity, Gender and the Struggle for Recognition* (2015b). McQueen (2015a, 2015b, 3) argues that understanding recognition as a basic human need depends on a “deficit model” of recognition, which mainly considers problems to arise when recognition is lacking or insufficient. He suggests that this perspective, which he attributes to Honneth, treats power as extrinsic to recognition processes, arguing that the desire for recognition is discursively produced rather than an inherent necessity. He emphasizes that “the more intractable problem is the ways in which recognition functions to regulate the realm of viable identities at an ontological level” (McQueen 2015a, 54). Other

scholars have also expressed concerns that recognition theory may obscure the connection between recognition and power dynamics by framing it as an inherently positive phenomenon (Connolly 2010; McNay 2008). For example, Butler argues that the desire for recognition can be tainted by or even complicit in social domination (2021b, 2021a). These critiques often interpret “recognition” primarily in the cognitive sense discussed above, related to social categorization and recognizability, rather than in Honneth’s narrower normative sense, which refers to acts. Consequently, these differing perspectives partly reflect different understandings of which phenomenon the term “recognition” should denote.

It should be noted that while both McQueen and Butler ground their perspectives in Foucault, Honneth’s focus on acts stems from his own critique of Foucault. After publishing *The Critique of Power* (1993), based on his dissertation, Honneth developed his recognition theory to better account for social dynamics and transformation, with a focus on emancipatory power struggles. In the book, he draws connections between Foucault and critical theory, criticizing Foucault’s systems-theoretic, functionalist approach for reducing power to a network of disciplinary institutions. Honneth argues that Foucault’s framework for understanding power essentially neglects the *social* as a site of strategic action and conflict. As Honneth (1993, 199) remarks, “Because of his structuralist beginnings, Foucault, as soon as he gives his theory of power the form of historical investigations, portrays subjects behavioristically, as formless, conditionable creatures.” Honneth’s emphasis on social action and transformation offers an alternative account of power and agency to Foucault’s. In fact, Butler effectively echoes this critique of Foucault in the debate with Honneth, pointing out that Foucault’s theory lacks the agency needed to explain gender performativity. Butler (2021b, 40) states, “Performativity as a form of self-making adds an agentic dimension to the Foucaultian theory that it otherwise seemed to lack.” Therefore, both Honneth and Butler recognize the importance of incorporating an agentic element in Foucault’s perspective on power. In my view, similar to Butler’s theory of gender performativity, an agentic view of recognition holds that norms of recognition can be altered through “performative” acts of recognition. By recognizing differently, recognizability can also be transformed.

Additionally, the idea that recognition theory obscures power often overlooks how struggles for recognition in Honneth’s framework relate to social movements such as feminism and involve transforming societal norms. Honneth (2014d, 76) describes the theory as owing “its entire critical impulse to social phenomena of lacking or insufficient recognition. It seeks to draw attention to practices of humiliation or degradation that deprive subjects of a justified form of social recognition and therefore of a decisive condition for the formation of their autonomy.” Honneth has also discussed “ideological” forms of recognition

that mainly reinforce social domination rather than expand autonomy and freedom. He describes ideological recognition as affirmation aligned with societal ideals that people find appealing and pursue willingly, even if it does not lead to tangible improvements for the individual or group in question. Exemplifying this, he states, “The emotional appeals to the ‘good’ mother and housewife made by churches, parliaments or the mass media over the centuries caused women to remain trapped within a self-image that most effectively accommodated the gender-specific division of labour” (Honneth 2014d, 77). Using Foucault’s terminology, Honneth (2014d, 90) states that “the power exercised by ideological forms of recognition is productive and not repressive.” To distinguish ideological recognition, Honneth relies on the idea of recognition as a practical attitude. Acts of recognition should be practical by involving tangible improvements in the physical world – such as behavior, habits, laws, institutional arrangements, or resource distribution. Whether acts of recognition result in tangible improvements is a matter of social interpretation, and struggles for recognition often center on advocating for such improvements. Some would likely argue that *all* recognition is ideological, but this is closer to the cognitive conception of recognition and comes with the risk of value relativism.

Unlike the view that framing recognition as positive risks obscuring power dynamics, I see this framing as valuable for exploring those very dynamics through Honneth’s action-based framework. Normative assessment requires accounts of the positive, and a positive view of recognition helps clarify motivations for struggles for change, including in the context of endometriosis. From this perspective, I see gender dynamics as interacting with recognition processes, shaping both personal identities and broader social dynamics. Gender relations marked by domination can significantly impact self-relations and the social category of gender. While my primary focus is on recognition, this relational and processual understanding shares affinities with both Beauvoir’s idea of becoming woman and Butler’s gender performativity. I also draw on Butler’s notions of “recognizability” and “frames of recognition,” which are directly related to recognition. Both Honneth’s and Butler’s theories are valuable here, but understanding their similarities and differences is important. Both support social ontologies influenced by Hegel, but as noted earlier, Honneth describes this aspect through the concept of “elementary recognition,” setting it apart from normative recognition. He also differentiates between normative recognition – acts that confer social status – and cognitive recognition, which involves discursive conditions and intelligibility. By integrating the theories of Butler and Honneth, I benefit from each philosopher’s contribution, as they theorize different aspects of the recognition process. However, in this study, I mainly use the term “recognition” in Honneth’s normative sense.

My main contribution to these ongoing discussions of recognition is to demonstrate how Honneth's interpretation of the Hegelian theme can be productively integrated into gender studies. By seriously engaging with Honneth's assertion that his theory offers a phenomenology of social experiences of injustice (Honneth 2002, 500, 2003a, 113–14), I develop empirically informed concepts that capture lived experiences of gender dynamics in the context of endometriosis. In doing so, I illustrate how gender studies can in turn enrich recognition theory by analyzing and conceptualizing the interplay between gender dynamics and various forms of recognition. Perceptions of conditions like endo, along with the suffering it entails, are shaped by gender relations and dynamics. The interviewees in this study share experiences of being dismissed, disbelieved, or misunderstood – across different spheres, including those involving medical settings, family and friends, and educational or workplace environments. By relating Honneth's framework of love, respect, and esteem to experiences of illness, I show how these forms of recognition are vital in shaping their experiences. The theme of recognition runs throughout the study as a whole and provides the thematic structure for the articles, each of which explores a specific facet of the gendered recognition of endo. In the next chapter, I explain how I identify these themes and develop the phenomenology of how gender and recognition shape experiences of endometriosis.

METHODOLOGY

This study began with a sense of curiosity about what it is like to live with endometriosis in Sweden, a country widely associated with gender equality, but where individuals with the condition still face significant obstacles. This curiosity resonates with a long philosophical tradition that links inquiry to wonder: both Aristotle and Plato famously traced the origins of philosophy to wonder.⁴³ The phenomenological tradition, in particular, is often portrayed as privileging wonder, ambiguity, and curiosity (Weiss et al. 2019, xiii). In my case, this curiosity extended beyond describing experiences of endometriosis to understanding how gender dynamics and processes of recognition shape those experiences. I therefore sought an approach that would allow me to explore the phenomenon in depth while remaining grounded in everyday life and to conceptualize the insights gained from my reflections.

Phenomenology is sometimes described as a method that restores our capacity to “stand in wonder before the world,” aiming to disrupt our habitual familiarity with it.⁴⁴ This perspective holds merit, as gaining a deeper understanding of specific phenomena often requires a certain level of wonder – in both senses of the word, including both curiosity and fascination. At the same time, there is a contradiction in defining phenomenology by wonder, particularly since its founder, Edmund Husserl, aimed to establish a rigorous scientific method for exploring an area previously overlooked by the sciences: the everyday lifeworld of people in general. His aim was to develop a technique capable of challenging our habitual and taken-for-granted ways of perceiving the world.⁴⁵ Moreover, the emphasis on wonder has been criticized for making promises that exceed its capacities. Bonnie Mann (2018a), for example, examines wonder across the works of Plato, Aristotle, Husserl, Merleau-Ponty, Irigaray, Sara Heinämaa, and Sara Ahmed, questioning the assumption that wonder itself possesses a purifying power over

⁴³ Through Socrates, Plato (1921, 55) suggests that “this feeling of wonder shows that you are a philosopher, since wonder is the only beginning of philosophy.”

⁴⁴ Merleau-Ponty borrows this formulation from Husserl’s assistant Eugen Fink (Merleau-Ponty [1945] 2012, 14, 348).

⁴⁵ In this regard, his method can be understood as delivering what Bertolt Brecht (1961) describes as an alienation effect (*Verfremdungseffekt*). Some scholars even suggest that Brecht, through his artistic practice, mobilizes a phenomenological methodology (Kelly 2020).

interests, judgments, and habits. While wonder may serve as a starting point for inquiry, it does not in itself guarantee a critical stance. A method driven by wonder therefore requires additional substance, which I intend to provide in this chapter.

A Phenomenology of How Gender and Recognition Shape Endo Experiences

To reiterate, this study aims to deepen the current understanding of how gender dynamics and recognition shape experiences of endometriosis. I propose that this aim can be achieved by employing an empirically informed phenomenology, based on the personal narratives of 15 individuals with endometriosis in Sweden. This chapter outlines my approach to capturing the typical features of their experiences through phenomenological interviews, highlighting the common threads that shape their realities with endo. Phenomenology, both a philosophical tradition and a method, guides the overall methodological framework. The chapter also describes the techniques I use to generate empirical material and develop the concepts that structure the analysis.

The reader is invited to take part in a shift of perspective. Beginning with wonder and embracing Husserl's ([1900–1901] 2001, 168) advice to “go back to the ‘things themselves,’” we move beyond viewing endometriosis merely as a medical fact and instead seek to understand how endo, as a phenomenon, appears and takes on meaning in the lifeworld. As a philosophy of experience, phenomenology explores the structures of phenomena from a first-person lifeworld perspective. Since its inception, phenomenology has provided detailed accounts of human existence, characterizing the subject as an embodied being that is socially and historically embedded in the world (Zahavi, 2019). Although illness is a core aspect of human existence, several scholars point out that it has received less philosophical attention than topics like death (Carel 2016, 1; Fisher 2014, 41).

Like social constructionism, phenomenology contrasts with the traditional medical perspective, which typically approaches disease as an objective physical condition to be explained through scientific knowledge (Lupton 2003, 50). However, while constructionist perspectives provide valuable insights, they fall short of capturing the subjective and embodied dimensions of first-person experiences (Carel 2016, 1; Fisher 2014; Slatman 2014). Moreover, the potential of phenomenological analysis in medicine is often overlooked (Svenaeus 2000), reflecting a broader neglect of the “human” side of medicine. Through its focus on lived experience, phenomenology enables exploration of the subjective, existential,

and social dimensions of illness (Fisher 2014). As Fisher (2014, 28) explains, phenomenology facilitates a 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.” The present study uses the interviewees’ narratives to *identify*, *describe*, and *analyze* the generalities and typical features of their experience.

While Husserl is widely regarded as the founder of phenomenology as a philosophical movement, Hegel also used the term phenomenology for his own philosophical project, and the two approaches share notable affinities.⁴⁶ For this reason, combining Hegelian recognition theory with a Husserlian phenomenological orientation provides a particularly fitting framework for the present study. Within this framework, the analysis involves contextualizing and historicizing the “what it is like” of experience (Al-Saji 2017) through the lenses of gender and recognition. Phenomenology has long been a valuable resource for feminist inquiry. As Alia Al-Saji (2017) notes, its impact on feminist theory can be seen through key sources, notable figures, and central themes. Feminist scholars have drawn on key sources like Husserl, Emmanuel Levinas, Jean-Paul Sartre, Frantz Fanon, Beauvoir, and Maurice Merleau-Ponty. From its beginnings, phenomenology addressed feminist concerns, even if not explicitly labeled as such, through notable figures like Edith Stein (2017) and Beauvoir ([1949] 2011). Moreover, phenomenology investigates central themes that are equally central to feminism, including embodiment, affectivity, perception, temporality, subjectivity, and intersubjectivity. Beyond this influence, Al-Saji (2017, 143) suggests that

⁴⁶ While Husserl is often credited as the founder of phenomenology, Robert R. Williams (1992) argues that the influence of earlier German philosophy is often overlooked. Notably, the first work to include “phenomenology” in its title is Hegel’s *Phenomenology of Spirit*. Williams (1992, 95–96) suggests that despite their differences in vocabulary, Hegelian and Husserlian phenomenology share key features. Both philosophers view phenomenology as a critical corrective to philosophy and draw from skeptical philosophy; Husserl uses the skeptical epochē, whereas Hegel describes his work as self-accomplishing skepticism. They both aim to overcome dogmatism, which Hegel understands as the suppression of alterity, or “the other” (Williams 1992, 105). Furthermore, both seek to establish a systematic science of conscious experience, aiming to guide philosophy toward understanding the lifeworld. Hegel’s *Phenomenology of Spirit* is sometimes subtitled “The Science of the Experience of Consciousness,” a description that could also apply to Husserl’s phenomenology. Similarly, Dermot Moran (2019, 7) suggests that Husserl ultimately aimed to develop his own phenomenology of Spirit. He highlights parallels between Husserl’s concept of “reduction” and Hegel’s “dialectics,” particularly in how Spirit evolves beyond the “natural attitude” in the pursuit of knowledge. In his later work, *Crisis* ([1936] 1978), Husserl even incorporates the concept of Spirit (*Geist*), and develops a historical-teleological reflection akin to Hegel’s approach. As a result, several scholars have noted parallels between *Crisis* and *Phenomenology of Spirit* (Natanson 1973; Inwood 2005).

the value of phenomenology for feminist inquiry is best appreciated when phenomenology is viewed not only as a tradition but also as a method. Feminist phenomenology extends this method by emphasizing how oppression, power, and privilege shape experiences – including those of illness. Feminist scholars have both applied and negotiated this method, as seen in the work of Linda Martín Alcoff (2006), Al-Saji (2010), Ahmed (2006), Young (2005b), Heinämaa (2003), Lisa Folkmarsson Käll (2009), Johanna Oksala (2016), and Gail Weiss (2008). Today, this field also includes feminist phenomenologies of illness and medicine (Käll and Zeiler 2014; Fisher 2014; Lajoie 2019), an area to which this study contributes.

In recent years, discussions of a “critical turn” in phenomenology have further developed these perspectives.⁴⁷ Al-Saji (2017) defines critical phenomenology as an expansion of the core phenomenological tool, the reduction, to include the naturalization of social oppression in experience. While I do not draw a sharp distinction between classical and critical phenomenology, both feminist and critical phenomenology share the combined analytical and transformative impulse already discussed in relation to critical theory. As Weiss et al. (2019, xiv) suggest, critical phenomenology can be understood as an “ameliorative” approach that not only aims to describe the world but also seeks to repair it. This involves examining how power relations shape experiences, and how structural, political, and institutional inequities manifest in personal biases and habits.

With regard to gender, Al-Saji (2017, 151) proposes a “thick intersectional approach” that considers how gendering takes shape within a thick nexus of experience involving coloniality, racialization, and more. This perspective parallels Käll’s (2009, 111) observation that the way bodies are sexed depends on a multitude of other factors, such as age, race, weight, dis/ability, sexual orientation, social and cultural position, etc. My understanding of gender dynamics aligns with this approach, with different factors coming to the fore depending on the theme discussed. In this study, I focus primarily on gender and its intersection with illness and dis/ability. Questions of identity are explored more explicitly in the discussion of “endo politics,” where dimensions such as gender identity, dis/ability, age, and ethnicity become particularly salient. Although class is not

⁴⁷ The expression “critical turn” is used for instance by “Puncta: Journal of Critical Phenomenology,” which published its first issue in 2018 (Puncta: Journal of Critical Phenomenology 2025). However, Salomon (2018) notes that the concept of “critical phenomenology” dates back to at least the 1980s, pointing in particular to Don Wellton and Hugh Silverman’s *Critical and Dialectical Phenomenology* (1987), a collection of papers from the annual meetings of the Society for Phenomenology and Existential Philosophy in 1984 and 1985. Other scholars, such as Mann (2018b), argue that phenomenology must already be critical to be feminist, citing Beauvoir as a central example.

used as a central analytical concept, I consider how illness affects education, work, and the interviewees' financial situation and outlook.

To understand how gender dynamics shape endo experiences, empirical information is vital. Through interviews with individuals living with endometriosis, I generate first-person narratives that offer rich and nuanced descriptions of their experiences. These narratives provide the empirical basis for what I describe as an empirically informed phenomenology.

An Empirically Informed Phenomenology

Phenomenology can engage with empirical material in multiple ways. A key distinction can be made between empirical research that incorporates phenomenological elements and phenomenological philosophy that draws on empirical material. This study fits into the latter category and is best described as an empirically informed phenomenology. Axel Honneth occasionally uses this term to characterize his recognition theory, referring to an empirically informed phenomenology of social experiences of injustice or, expressed differently, of structures of mutual recognition in the lifeworld (Honneth 2003a, 114, 2002, 500). Although he does not elaborate on his use of phenomenology, this description aligns well with the approach adopted here. I use the term “empirically informed” to emphasize that theory, particularly the concept of recognition, guides the overall research process and theorization. This differs from a grounded theory approach, which is more strictly inductive.

Phenomenological philosophy has long engaged with empirical material in a systematic manner, as seen in the work of Beauvoir ([1949] 1956) and Merleau-Ponty ([1945] 2012). Moreover, phenomenology has had a wide influence in the social sciences and qualitative research, serving as a theoretical framework that offers valuable concepts, such as the *lifeworld*, *intentionality*, and the *lived body*. Prominent sociologists, including Alfred Schutz, Peter L. Berger, Thomas Luckmann, and Harold Garfinkel, have drawn extensively on phenomenological themes, concepts, and methodologies to analyze the social sphere (Zahavi 2019b, 105).

In recent decades, a number of approaches have sought to combine phenomenology with qualitative research methods, integrating fields such as ethnography, anthropology, psychology, and nursing with phenomenology or hermeneutical perspectives (see Høffding 2019; Zahavi 2019b). Notable frameworks include Amedeo Giorgi's (2009) descriptive phenomenological method and Jonathan Smith's (2009) IPA, both within psychology, as well as Max van Manen's (2014) hermeneutic phenomenology in pedagogy. However, these frameworks have

faced criticism for not sufficiently incorporating phenomenological philosophy (Gallagher 2012, 306; Höffding 2019).⁴⁸

Dan Zahavi (2019a) offers several clarifications that are helpful for understanding these debates. He argues that approaches such as Smith's IPA should be regarded as phenomenologically informed qualitative research, rather than phenomenological philosophy proper, because they primarily explore the experiences of specific individuals. Zahavi also criticizes van Manen's account of phenomenology for being superficial and trivialized. Contrary to van Manen's repeated formulation of phenomenology as addressing the question "What is this lived experience like?" (van Manen 2017, 776), Zahavi emphasizes that phenomenology pursues broader philosophical aims. Experiential descriptions are not ends in themselves but serve a systematic philosophical investigation of the structures of experience.⁴⁹ Central to this project is the phenomenological reduction and epochē. Zahavi stresses that these methodological steps do not primarily aim at clarifying the meaning of experiences, but at suspending the "natural attitude" in order to adopt a phenomenological attitude. This shift enables analysis of *how* and *as what* objects are given to us – how they are constituted by consciousness (Zahavi 2019a, 903). This understanding resonates with my own approach to endometriosis as a phenomenon, as discussed below.

The use of interviews in this study aligns with a trend observed in recent decades, in which an increasing number of scholars in phenomenological philosophy engage in systematic qualitative research, conducting interviews and observations with specific philosophical goals. De Boer and Zeiler (2024) characterize this emerging field as "qualitative phenomenological philosophy." This integration of phenomenology and qualitative research also resonates with Fisher (2014, 28), who calls for "a return to the 'doing' of phenomenology, in addition to the (often overemphasized) historical scholarship." Fredrik Svenaeus (2000, 6) similarly highlights this link between phenomenology and empirical research, characteriz-

⁴⁸ Both van Manen and Giorgi have raised concerns about the philosophical foundations of Smith's IPA. Van Manen (2017a) suggests that Smith conducts a psychological analysis rather than a proper phenomenological one, while Giorgi (2011) highlights Smith's "confused" use of phenomenological concepts, especially the reduction and bracketing. Commenting on these debates, Zahavi (2019a) argues that both Smith and van Manen have contributed to the confusion about phenomenology and its core ideas, especially regarding the reduction and the epochē. For a phenomenologically informed discussion of how effectively these methods succeed in using phenomenology in qualitative research, see also Zahavi (2019b).

⁴⁹ Zahavi exemplifies this by describing Heidegger's exploration of boredom – highlighted also by van Manen (2017b) – as an effort to understand ontological questions, based on Heidegger's view that ontology and phenomenology are interconnected rather than separate enterprises.

ing phenomenology as a philosophical approach “that preserves the drive towards generality, concept and abstraction, but nevertheless acknowledges its relation to other disciplines which carry out more specific and empirical research.”

The aim of qualitative research is to enhance the scientific community’s understanding of particular phenomena. Yet defining what makes qualitative research “qualitative” is not straightforward, since it does not adhere to a single methodology or set of materials. Patrik Aspers and Ugo Corte (2019) suggest that a key feature of qualitative research lies in its capacity to generate *new knowledge* and provide *deeper insights* by making *new distinctions*. They suggest that qualitative research is best defined by its outcomes, the type of knowledge it produces, and the methods used to attain it. They therefore characterize qualitative research as “an iterative process in which improved understanding to the scientific community is achieved by making new significant distinctions resulting from getting closer to the phenomenon studied” (Aspers and Corte 2019, 155). This description aligns closely with the goals of the present study. My approach to “getting closer” to the phenomenon of endo involves generating and analyzing empirical material while remaining guided by Husserl’s call to go back to the “things themselves.” Through phenomenological analysis of interview narratives, I aim to identify typical features of endometriosis experiences. In doing so, the study develops empirically informed concepts that contribute to a deeper understanding of the phenomenon.

To generate empirical material, I use an adapted version of the phenomenological interview framework developed by Simon Høffding and Kristian Martiny (2016). This framework combines qualitative research with phenomenological philosophy and consists of two interconnected and overlapping tiers: the interviews themselves and the phenomenological analysis of the descriptions generated through them (Høffding and Martiny 2016, 543–44). The goal of the interviews is to gain rich, first-person descriptions of lived experience. These accounts provide the empirical foundation for the phenomenology of endometriosis developed in this study. The theoretical framework also informs the interview process by shaping the questions asked and guiding how experiences are articulated (Høffding and Martiny 2016, 543–44). During analysis, I use these descriptions to identify generalities and typical features of experience. Both steps are essential since I do not have direct access to the first-person perspective or the structural features of these experiences. Conversely, the generalities and typical features I identify are typically not directly available to the interviewees themselves. They are usually not articulated directly during the interview but emerge from later analysis. Although these two tiers are methodologically distinct, they are in epistemic continuity.

Høffding and Martiny do not claim to have invented a new method. Rather, their approach draws inspiration from ethnographic interviewing while incorporating specific phenomenological commitments. In this study, these commitments can be summarized as follows: (I) Going to the things themselves; (II) Identifying generalities and typical features of experience; (III) Understanding subjectivity as irreducible to objectivity; (IV) Understanding experience as embodied, embedded, and enacted.⁵⁰ Taken together, this methodological approach combines phenomenological analysis with qualitative interviews to investigate how gendered dynamics and recognition shape the lived experiences of endometriosis. After introducing the empirical material, I expand further on how these commitments guide the analysis.

Generating Illness Narratives

To generate empirical material for the phenomenological analysis, I conducted in-depth semi-structured interviews with 15 individuals who shared their experiences of endometriosis. These interviews produced illness narratives that serve as the empirical basis for the analysis. Since the aim of the study is to deepen the understanding of how gender dynamics and recognition shape experiences of the condition, I sought individuals with first-person experiences with endometriosis. In-depth interviews are particularly well-suited for this purpose because they enable participants to articulate how their experiences are perceived, interpreted, and lived. Semi-structured interviews enable interviewees to narrate their experiences in their own terms while maintaining a focus on specific themes.

The knowledge produced during an interview arises from the interaction between the interviewer and the interviewee, as experiences are articulated and reflected upon within the interview situation. As Svend Brinkmann and Steinar Kvale note, it is “literally an inter-view, an inter-change of views between two

⁵⁰ Høffding and Martiny describe the commitments as follows: (1) go to the things themselves, (2) subjectivity has irreducible and invariant structures, (3) subjectivity is irreducible to objectivity, and (4) experience is embodied, embedded and enactive (Høffding and Martiny 2016; Høffding 2019). I have thus replaced the second commitment’s “irreducible and invariant structures” with Fisher’s (2014) “generalities and typical features.” This wording emphasizes the typical while steering clear of ideas related to rigidity, universality, or permanence. Similarly, Iris Marion Young highlights the typical in her pivotal analysis of feminine body comportment. Young articulates that she does “not claim universality of this typicality (...) and the phenomenological descriptions derived from it” (Young, 1980, p. 139). She posits that this aligns with the existential concerns with the situatedness of human experiences. My approach to the interviewees’ shared experiences mirrors this perspective. I seek to pinpoint typical elements in their narratives about their lived world, which is inherently social and historical, rather than to uncover a universal truth regarding all experiences with endometriosis. See also Oksala’s (2023) critical discussion of the eidetic reduction.

persons conversing about a theme of mutual interest” (Brinkmann and Kvale 2015, 4). The interview therefore does not simply extract information from participants but generates knowledge through a dialogical process in which experiences are articulated, clarified, and reflected upon.

Although qualitative research interviews have been an integral part of the social sciences for nearly a century, Brinkmann and Kvale argue that it is only in recent decades that these interviews have gained attention in methodological discussions. They propose that while qualitative inquiry is deeply rooted in philosophy, researchers often have limited access to philosophical frameworks that help them conceptualize the type of knowledge generated by these interviews – knowledge that pertains to the lived experiences of everyday life from a first-person perspective (Brinkmann and Kvale 2015, 59). Brinkmann and Kvale have developed what they call the *lifeworld interview*, a widely used approach in qualitative research. The concept of the lifeworld reflects its phenomenological inspiration, which the authors believe extends broadly to qualitative research (2015, 35–36):

[P]henomenology has been extremely significant in the development of qualitative research, not least with respect to establishing steps and procedures of analysis and thereby contributing to making qualitative inquiry a legitimate scientific endeavor. (...) [I]ts advocates point to its capacity for studying first-person experiences, its rigorous methodology, and its success in establishing many forms of qualitative research on a firm basis.

If we accept the viewpoints of Brinkmann and Kvale, conducting interviews in qualitative research inherently draws from phenomenology, although this is not always made explicit. Integrating qualitative research interviews with phenomenology therefore does not introduce a foreign element. Rather, it builds on an affinity that already exists between qualitative interviewing and phenomenological inquiry. In the following sections, I describe the process for recruiting and selecting interviewees for the study, as well as the ethical considerations involved.

Recruiting and Selecting Interviewees

To participate in the study, the interviewees had to meet two inclusion criteria. Given the sensitive nature of living with a chronic illness, I included only adults, defined as individuals aged 18 or older. Although symptoms of endometriosis can present as early as during the very first menstruation, this decision meant that individuals younger than 18 were not included in the study. While this choice may limit the range of experiences captured, the participants had already passed

through this stage of life and illness, allowing them to provide insights into their adolescent experiences as well.

The second criterion required participants to have a medically confirmed diagnosis of endometriosis. I chose this criterion to ensure that the experiences described were specifically linked to this condition, rather than to another illness with similar symptoms. This does not mean that I excluded accounts related to other conditions during the interviews. Research indicates that comorbidity is significantly more common in individuals with endometriosis than among those without it, and I therefore view comorbidity as an integral part of the endo experience.⁵¹ Using diagnosis as an inclusion criterion can present challenges. It may complicate participant recruitment, particularly since many individuals with endo struggle to secure an accurate diagnosis. By focusing on those already diagnosed, the study necessarily excludes individuals who are still seeking a diagnosis or those who remain undiagnosed. Moreover, prioritizing diagnosis requires adopting a medical criterion for inclusion in a study that otherwise seeks to move beyond a purely medical perspective. Despite these potential limitations, recruitment proved unproblematic. Furthermore, the participants shared detailed accounts of their experiences before receiving a diagnosis, confirming that this phase is well represented in the study. Indeed, difficulties in obtaining a diagnosis emerged as a central theme in the analysis and are discussed in all of the articles.

Participants were primarily recruited through online platforms and social media channels. I created a dedicated website to share an information letter, which can be found in *Appendix I: Information Letter (in Swedish)*, along with project details. I contacted the Swedish Endometriosis Association (Endometriosföreningen), which shared my letter on both Facebook and Instagram. I also posted the letter on my personal Facebook page, resulting in over 230 shares. Within the first 24 hours, I received nearly 200 responses in my inbox. This overwhelming response not only reflects the prevalence of the condition but also highlights the strong desire among many individuals to share their experiences. Many respondents wrote comments such as, “I am more than happy to participate so that people can understand what it is *really* like to live with endo.” Others expressed their gratitude, saying, “Thank you for conducting this study; it is urgently needed,” or “I am so grateful that you are doing this; this is something

⁵¹ For individuals with endometriosis, the adjusted risk of developing a comorbid condition is at least twice as high for nine comorbidities: infertility/subfertility, ovarian cyst, uterine fibroids, pelvic inflammatory disorder, interstitial cystitis, irritable bowel syndrome, constipation/dyschezia, ovarian cancer, and endometrial cancer (Surrey et al. 2018).

that is not acknowledged in society.”⁵² During the interviews, some interviewees expressed a particular eagerness to engage in a gender studies project, highlighting the importance of focusing on gender and power dynamics. This may indicate that the project attracted individuals who are more likely to interpret their illness in political terms related to gender and justice. Overall, these responses suggest that many respondents view the study as part of a broader process of increasing societal recognition of endometriosis.

The next step involved the challenging task of selecting interviewees from the large number of responders. My goal was to include individuals who could provide rich and detailed accounts of living with endometriosis. I primarily focused on factors related to their illness experiences, including the severity of their symptoms, the age at diagnosis, the time it took to receive a diagnosis, the types of medical treatments they underwent, and the effectiveness of their current therapies. I aimed to include a variety of experiences, ranging from cases in which treatment was experienced as relatively successful to situations in which treatment had limited effect. This variation made it possible to analyze typical patterns across different illness trajectories. In addition, I sought to ensure a degree of diversity among participants.

I therefore included participants based on other aspects highlighted in their response letters, including age, gender identity, sexual orientation, family situation, occupational status, and ethnicity.⁵³ Although this study does not conduct a formal intersectional analysis, I see gender dynamics and experiences of illness as shaped by the interplay of multiple social identities, including ethnicity, age, class, and dis/ability status. Nevertheless, the primary focus of the study is the relationship between gender and illness. I therefore did not aim for strict representativeness across all identity categories. Rather than achieving statistical representativeness, the goal was to generate rich narratives, allowing me to identify typical features of how endometriosis is experienced and interpreted. Recruiting participants mainly via online platforms and social media may also have influenced the initial sample, as different groups tend to prefer different online platforms, particularly in terms of age, which can affect the diversity of the sample even before selecting interviewees.

⁵² This aligns with Ann Oakley’s observation that women interviewees were generally enthusiastic about taking part in her research. Oakley also cites Janet Finch, who states: “Women are almost always enthusiastic about talking to women researchers” (Finch 1984, 72).

⁵³ I used occupational status as a proxy for socioeconomic status, considering both the occupation as such and whether the respondent could engage in paid work at all or was unable to work due to illness. Since the respondents generally did not provide information about their ethnic background, I used names as an ethnicity indicator. Although name-based classification has its limitations, it is sometimes used to overcome data scarcity (Mateos 2007).

Each interview is unique, and determining how many to conduct can be tricky. The decision is also shaped by practical considerations such as available time, resources, and the planned format of the interviews. Before beginning recruitment, I had decided to aim for between 15 and 20 participants. This number would enable me to conduct in-depth interviews and identify typical features of experiences while maintaining the project's timeline and accommodating potential dropouts. After receiving the responses, I decided to conduct the interviews in three cycles, each involving five participants. After each cycle, I reviewed the material and performed a preliminary analysis of the saturation level achieved up to that point. The concept of saturation is complex and has been widely discussed since it was first introduced in the context of "theoretical saturation" (Glaser and Strauss 1967). My assessment was guided by the idea of a "saturation of knowledge" (Bertaux 1981). This concept refers to how initial interviews often yield a wealth of new information and surprising insights; yet over time, researchers begin to recognize patterns in the responses. As a result, later interviews tend to corroborate existing descriptions rather than introduce novel information.

As the interviews progressed, I began to observe recurring themes and patterns in the narratives, rather than encountering entirely new types of experiences. By the end of the third cycle, after interviewing a total of 15 participants, I concluded that I had reached a satisfactory level of saturation. At this stage, I had identified the three main thematic areas discussed in the articles: temporality, epistemic practices, and political mobilization in relation to the recognition of endometriosis. Greg Guest et al. (2006) suggest that conducting 12 interviews within a homogeneous group is typically sufficient to reach saturation. In their approach called "Qualitative Critical Phenomenology," Marjolein De Boer and Kristin Zeiler (2024) recommend ten to 20 interviews as a general guideline, as this yields rich data while allowing for participant dropouts. They emphasize that the actual number of interviews conducted should ultimately depend on when saturation is reached in the analysis. While each individual story I encountered was distinct, after the third cycle, I felt I had generated rich descriptions of frequently recurring situations and events that conveyed something typical and significant about how endo is experienced and recognized.

The Interviewees

The 15 interviewees, aged between 18 and 62 at the time of the interview, came from various regions across Sweden. Among them, listed in *Table 1*, 14 identified as women and one as non-binary. Their experiences with endometriosis varied greatly; while some endured severe pain that significantly limited their daily activities, others reported leading "normal" lives, which they described as including

activities such as working and exercising. In most cases, symptoms such as pain and heavy bleeding began at or soon after menarche, occurring between the ages of ten and 12, but the age at which they were diagnosed varied widely. Some had experienced symptoms since adolescence but believed these symptoms were “normal,” while others sought healthcare early but struggled to be taken seriously by doctors. In many instances, the condition affected their fertility and caused discomfort during penetrative sex, influencing their intimate relationships, family life, and overall intimacy. For some, the diagnosis was delivered during fertility investigations or in connection with treatment for other conditions, such as ectopic pregnancy. Notably, two interviewees were related – a mother and daughter. It was the daughter who contacted me, noting her mother’s own experience with endometriosis, which led me to conduct a joint interview with both, resulting in a total of 14 sessions with 15 participants.

<i>Interviewee</i>	<i>Age</i>	<i>Brief Illness Biography</i>
1.	23	Symptoms began shortly after menarche at age 10, diagnosis at 21 years old
2.	55	(The mother) Symptom debut at age 12, diagnosis at 40 years old
3.	30	(The daughter) Symptom debut at age 12, diagnosis at 15 years old (“I was lucky”)
4.	45	Symptom debut at menarche, diagnosis at 29 years old
5.	26	Memories of pain from adolescence, severe symptoms at 21, diagnosis at age 22
6.	34	Symptom debut at age 11-12, diagnosis at 23 years old
7.	62	Severe pain during adolescence, diagnosed at age 32, linked to a fertility investigation
8.	48	Symptom debut in her 40s, hysterectomy at 45, diagnosis at 48 years old
9.	36	Symptom debut at age 12-13, diagnosis at approximately 28 years old
10.	28	Increasingly worse symptoms during high school, diagnosis at 27 years old
11.	28	Symptom debut at age 13, diagnosis at 23 years old
12.	37	Symptom debut during adolescence, diagnosis at 29, treatment today is effective
13.	41	Symptom debut at menarche, diagnosis at 39 years old
14.	18	Symptom debut at menarche, diagnosis at 16 years old
15.	30	Symptom debut at menarche, chronic symptoms at 22, diagnosis after 25 years old

Table 1: The Interviewees

All of the interviews took place in 2018. Later that year, the National Board of Health and Welfare in Sweden released the long-awaited national guidelines for endometriosis care. These guidelines highlight how endometriosis can cause significant suffering for patients throughout their lives, leading to considerable societal costs.⁵⁴ Consequently, my interviews represent the last “generation” prior to the implementation of national guidelines in Sweden. The interviews took place at various locations chosen by the interviewees. While I usually prefer in-person interviews for their smooth conversational flow, geographical constraints sometimes created challenges. In those instances, participants suggested using Skype, which I agreed to. Three interviews were conducted via Skype, while the remaining 11 were face-to-face meetings – two at the interviewees’ homes, four at cafés, and five in my office or other locations at Stockholm University. All interviews were audio-recorded and subsequently transcribed into a more analysis-friendly format, focusing on the content while making minor adjustments to enhance readability. Non-verbal cues and pauses were typically omitted unless they provided significant insights into sentiment and mood.

Along with the interviews, I have collected memorabilia related to endometriosis that offers context about the environment surrounding the interviewees. The collection process lacked a strict systematic approach; it reflected my curiosity and attention, particularly during the first two years of the project, starting in 2017, and during the intensive interviewing phase in 2018. The collection includes photos from the two EndoMarch events in Stockholm in 2017 and 2018, news articles featuring celebrities like Lena Dunham sharing their “endo stories,” debates and discussions from online forums, feminist memes and art related to endo and menstruation, and the Swedish novel *Nora Eller brinn Oslo brinn* (Frid 2018), which addresses two “forbidden” illnesses: jealousy and endometriosis. Additionally, I have a pin depicting a uterus in the shape of a rainbow and a yellow T-shirt I bought at the first EndoMarch featuring the slogan “Eight years is not OK!”. I have also followed various groups and accounts on Facebook and Instagram, primarily from Sweden, the United States, and the United Kingdom. I have taken note of the hashtags such as #endowarriors, #endosisters, #endostories, and #endoart. Through this online engagement, I became aware of Niagara Falls being illuminated in yellow on March 26, 2018, to honor Endometriosis Awareness Month.

At the beginning of the study, I had not decided what to do with these memorabilia. Ultimately, I consider it secondary material that primarily helps improve

⁵⁴ In 2018, the Swedish National Board of Health and Welfare estimated that 250,000 persons suffered from endometriosis in Sweden, costing approximately 51 000 SEK (5 600 Euro) per patient per year, which is double the cost of care for the general population (Boström et al. 2012; National Board of Health and Welfare 2018).

my understanding of common terminology, symptoms, symbols, and societal issues surrounding endo. This material has allowed me to delve deeper into the “messy empirical reality” (Zala et al. 2020) surrounding the interviewees and better comprehend their social reality, similar to a smaller-scale ethnographic immersion.⁵⁵ It has provided contextual knowledge and helped me approach the interviews with a degree of familiarity, particularly when discussing topics like online activity and the political mobilization for national guidelines. With this contextual understanding, I was able to ask questions about the interviewees’ involvement in social forums and political events, or their perceptions of media coverage – topics that might not have been explored if I had taken a narrower focus. Additionally, this knowledge was beneficial in determining when I had reached saturation in my primary material, as the main themes I identified – temporality, epistemic practices, and political mobilization – were also present in the secondary material, confirming their significance and prevalence in experiences of endo.

Research Ethics and Reflexivity

This study complies with the research ethics guidelines established by the WHO Research Ethics Review Committee (ERC) and the Swedish Research Council. Additionally, it has been approved by the Regional Ethical Review Board in Stockholm.⁵⁶ Beyond these formal requirements, which include voluntary participation, informed consent, the right to withdraw, confidentiality, and pseudonymization, I also consider other aspects of research ethics. The way researchers conduct their studies and engage with research participants is critical, particularly since it is the researchers who typically initiate the relationship. Researchers have authority over what is said and done, and they can gain prestige and power from their research (Ellis 2007, 5).

In her article “Telling Secrets, Revealing Lives: Relational Ethics in Research With Intimate Others,” Carolyn Ellis proposes a *relational ethics* framework that “requires researchers to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences” (Ellis 2007, 1). Although Ellis primarily focuses on ethnography and

⁵⁵ The concept of immersion derives from Bronislaw Malinowski’s (1922, IX) work, where he described the ethnographer’s goal as grasping the participant’s “point of view, his relation to life, to realise *his* vision of *his* world.”

⁵⁶ The study complies with the “Ethical standards and procedures for research with human beings” developed by the WHO Research Ethics Review Committee (ERC), and the general guidelines for Swedish research ethics (Swedish Research Council 2019; WHO 2019b), and it has been approved by the Regional Ethical Review Board in Stockholm (Dnr: 201771455-31).

the deep connections that often develop over time – sometimes resulting in mutual friendships between the researcher and participants, whom she refers to as “intimate others” – many elements of her approach are relevant to the current study. For instance, even though I met the interviewees only once and did not establish long-term relationships, it is still appropriate to view the interview as an intimate encounter. Discussing deeply personal topics, such as living with a chronic illness like endometriosis, can evoke strong and difficult emotions. It requires participants to reflect on their bodies, their experiences of suffering, and the impact of the illness on their sexuality, intimate relationships, and life plans.

Furthermore, I believe that the relationship between the researcher and participants begins even before the interview takes place. It starts with the design of the project, the formulation of information related to the project, and the initial contact with each potential participant. This relationship continues after the interview has concluded and ultimately culminates in the final written text. This perspective informs my understanding of informed consent, which can be described as a form of “process consent” (Ellis 2007, 23). Before each interview, participants were asked to sign an Informed Consent Form. This form included an information letter detailing the terms of participation, which emphasized voluntary participation and the right to refuse or withdraw at any time, as well as ensuring confidentiality and pseudonymization.⁵⁷ During the interview, I reiterated this information verbally to ensure that participants had the opportunity to ask any questions about their involvement. In addition to their right to withdraw, each interviewee had the opportunity to review either the full transcripts or selected excerpts from the interviews that I planned to publish. This process enabled the interviewees to influence how they are represented in my work. Transforming the often chaotic reflections shared during interviews into structured and coherent narratives carries certain risks. We may inadvertently reduce or oversimplify complex thoughts into brief, neat quotes. Diana Mulinari (1999) refers to this phenomenon as the “silent violence of the soft method,” highlighting a specific risk in qualitative research. Although we cannot entirely eliminate this risk, giving the interviewees the opportunity to review interview documentation can help mitigate it. However, most interviewees opted not to read the transcripts, and none raised any concerns after doing so. Instead, they conveyed their trust in me and the process.

To further clarify the concept of relational ethics, Ellis (2007) refers to two dimensions of ethics proposed by Marilys Guillemin and Lynn Gillam: procedural ethics and situational ethics. *Procedural ethics* refers to the standards typically

⁵⁷ The letter and form can be found in *Appendix II: Information Letter and Informed Consent Form (in Swedish)*.

established by research ethics review boards, emphasizing key aspects such as informed consent, confidentiality, and privacy rights. *Situational ethics* addresses unforeseen events that may arise during an interview. For example, an interviewee might feel uncomfortable with certain questions or exhibit strong emotions that could be difficult to manage in a public setting. Given the intimate and potentially sensitive nature of discussing life with illness, I prioritized allowing the interviewees to choose their own interview locations. I suggested various options, such as their homes, a public café, or my office at the university, but they were also free to propose alternative locations that they preferred. One interview conducted via Skype turned out to be particularly emotional, suggesting that it may be easier to express feelings like sadness when at a distance and in the comfort of one's own home. While technologies like Skype become part of our "embodiment relation" (Ihde 1990), they create a physical separation between the interviewee and me, which may make the encounter feel less intrusive. Additionally, the home is often a space of comfort and familiarity, as widely reflected in metaphors and expressions like "feeling at home," "Das Unheimliche," or Husserl's "home world" and "alien world" (Waldenfels 1990; I. M. Young 2005a). The levels of emotional expressiveness also vary among individuals. The interviews conducted at cafés also revealed a mix of both positive and negative emotions, and I did not find the public setting to be a hindrance, aside from the less-than-ideal sound quality of the audio recordings due to background noise. Throughout each interview, it was important to stay attentive to how the conversation unfolded. I made it a point of reminding participants that they could skip individual questions, take breaks, cancel the interview, or withdraw from the study entirely if they felt uncomfortable at any time, but none of them expressed such needs.

In addition to procedural and situational ethics, Ellis' relational ethics draws on ethics of care, feminist ethics, and feminist communitarian ethics. Relational ethics "recognizes and values mutual respect, dignity, and connectedness between researcher and researched, and between researchers and the communities in which they live and work." (Ellis 2007, 4). This approach can be summarized by the open question, "What should I do now?" rather than the directive, "This is what you should do now" (Ellis 2007, 4). Relational ethics emphasizes the importance of being responsive to others, rather than merely adhering to pre-established codes of conduct. It provides a broader framework for engaging with others, informed by both procedural and situational elements, while also incorporating values from feminist research. In this study, relational ethics is closely tied to the concept of intersubjectivity and openness to the experiences of others. The interview itself becomes an integral part of the embodied lived experience of both interviewer and interviewee, as it involves "a mutual crossing of boundaries

that enacts the very means through which embodied subjects are both constituted, and undone“ (Shildrick 2009, 23).

In response to the intersubjective and sensitive nature of the interviews, I sought to build rapport through “empathic listening” (Chmielewski 2017). This involved showing keen interest in what the interviewee shared and following up with questions to gather specific details. Research on what constitutes good listening in qualitative research emphasizes that effective listening is crucial for generating rich data, and thereby enhances the quality of qualitative research. While many studies on interviewing focus on outlining the steps involved, developing interview guidelines, and discussing how to formulate questions, often insufficient attention is paid to the interaction between the researcher and participant, particularly the aspect of listening (Lavee and Itzchakov 2023).

Einat Lavee and Guy Itzchakov find this lack of focus surprising, as good listening is vital for gaining detailed information, building rapport with the interviewees, and helping them feel comfortable sharing their inner life experiences. The quality of listening can directly influence the knowledge produced. High-quality listening has been shown to boost psychological safety and reduce the speakers’ social anxiety and defensiveness. It can enhance cognitive flexibility, which is crucial for enabling rich descriptions. In contrast, inadequate listening can disrupt the participants’ thought processes, leading to shorter, less fluent narratives that may lack coherence (Lavee and Itzchakov 2023). This indicates that effective listening is not only essential for maintaining research ethics but also for ensuring research quality. As Janice Morse (2020, 4) notes, “excellent research requires excellent interpersonal skills in order to obtain good data.” Specifically, I focused on the three facets of good listening described by Lavee and Itzchakov (2023), which include *attention*, *comprehension*, and *relational components*. To demonstrate attention (being fully present), I turned off my phone’s sound to avoid distractions and maintained eye contact. To indicate comprehension (signal understanding), I asked follow-up questions and checked if they wanted to add anything. Regarding the relational components (demonstrating acceptance, empathy, and a non-judgmental attitude), I thanked them for participating, nodded, and expressed empathy when the interviewees discussed challenging or painful situations. If I sensed that an experience had been especially difficult, I acknowledged it verbally rather than striving to remain “neutral.”

Another factor that may have influenced rapport during the interviews was my willingness to be open about my own experience of living with chronic pain due to a work-related back injury. While I did not spend much time discussing my personal story, I sometimes mentioned it as a motivation for my research into experiences surrounding gender, chronic illness, and pain – especially if the interviewee asked. I might share whether I had tried the same painkillers as they

had or discuss common activities for alleviating pain, such as taking hot showers. This approach can demonstrate familiarity with aspects of illness experiences and highlighted my personal connection to the research. Generally, I focused on being attentive and encouraged detailed descriptions of their lives with endo. I tried to remain as open as possible to each interviewee's portrayal of their experiences.

This approach does not guarantee rapport, as each interaction is unique and our being-in-the-world is inherently mooded (Heidegger [1927] 2010). Rachel Thwaites notes, "in many ways, empirical research is a performance and the identity one projects as a researcher in this situation is created through that particular situation and time" (Thwaites 2017, 4). Since we cannot fully control the emotions we display or evoke in others, this interplay is a fundamental aspect of all intersubjective encounters. Nevertheless, I aimed to uphold my responsibility by responding with care to the participants before, during, and after the interviews, which includes how I ultimately represent their narratives in the written text. After generating the empirical material, the subsequent step was to conduct the analysis, adhering to the four phenomenological commitments I will now outline.

Commitment I. Going to the Things Themselves!

We perform the epochē – we who are philosophizing in a new way.⁵⁸

Endo as a Phenomenon

How does endometriosis appear in the daily lives of interviewees? I propose that it manifests as the phenomenon of "endo," a term I use to capture how the condition appears and is lived in everyday experience. The first phenomenological commitment I adopt is rooted in Husserl's classic dictum ([1900–1901] 2001, 168), to "go back to the 'things themselves.'" This phrase expresses Husserl's goal of returning to how things are given to us in experience, rather than relying on abstract preconceptions or assumptions. In the present study, this entails focusing on endo as a phenomenon as it is lived and experienced. This approach emphasizes the significance of experiences, suggesting that a deeper understanding of endo is best achieved by beginning with first-person accounts from those living with the condition.

As illustrated in *Figure 1*, I understand the phenomenon of endo as constituted not only by the medical diagnosis of endometriosis but also by the ways it is

⁵⁸ Husserl ([1936] 1978, 151).

shaped by gender dynamics and recognition processes. I therefore approach endometriosis not merely as a biomedical condition but as the phenomenon of “endo” to explore how it appears in lived experience. “Endo” is also an emic term,⁵⁹ used within the endometriosis community and frequently adopted by patients, activists, cultural critics, and scholars.⁶⁰ For this reason, it provides a suitable term for describing how the condition manifests in everyday life.

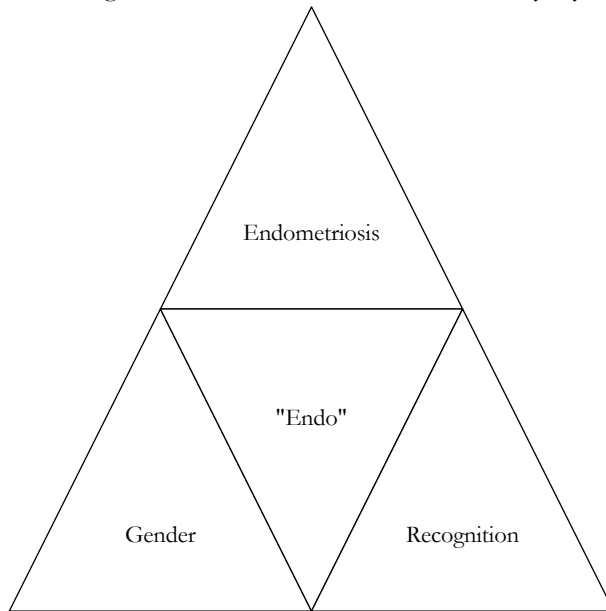


Figure 1: Endo as a Phenomenon

Phenomenology explores the structures of experience by examining phenomena – that is, how things appear and present themselves in everyday life from a first-person perspective. The phenomena studied can include everyday objects, events, or memories, as well as more abstract concepts such as time, others, or the self. In the present study, the phenomenon under investigation is endo. In

⁵⁹ “Emic” refers to the specific language used by cultural insiders, reflecting the point of view of the community. For more background on the terms “emic” and “etic,” see Mostowlansky and Rota (2020).

⁶⁰ Cara E. Jones uses “endo” and “endo existence” with reference to cultural critics and activist organizations who argue that: “Just as multiple sclerosis was shortened to MS decades ago (...) [e]ducating about the disease and making it a little more manageable and a little less formidable starts with the public being able to pronounce its name” (Ballweg 2004, xxiii quoted in Jones 2016, 567). Ella Shohat uses “endo discourse (...) to encompass a whole textual body produced around endometriosis that refers both to hegemonic medical and alternative discourses. Although physicians use the official name ‘endometriosis,’ it is at times referred to as ‘endo’ in self-help groups” (Shohat 1992).

her discussion of the illness experience, Linda Fisher suggests that a phenomenological approach can help differentiate and analyze “a view from without” and “a view from within” in the context of illness (Fisher 2014). These differing viewpoints correspond to the common distinction between disease and illness. Whereas “disease” refers to the biomedical condition, “illness” typically addresses the subjective, experiential, and situational dimensions of health (Fisher 2014).⁶¹ In relation to endo, several views “from within” could be imagined. Gynecologists, relatives, and friends all live “with” endo to some extent. My primary focus, however, remains on individuals diagnosed as “having” the disease. It is their lifeworld, standpoint, and first-person perspective that this study seeks to understand.

Many of Husserl’s key concepts and distinctions are valuable tools for analyzing endo experiences. In particular, I draw on the notions of the *natural attitude*, *lifeworld*, *bracketing*, *epochē*, *noema*, *noesis*, and *essence*. Husserl emphasizes that phenomenology is not about defining what something is, but rather about *how* it presents itself – its manners of givenness (Husserl [1936] 1978, 146). Adopting Husserl’s call for a return to the things themselves should not be interpreted as an investigation into the essence of endometriosis as such. Instead, it concerns how endo appears to those who experience it. In other words, the focus is on how endo is given to the interviewees within their lived experience. This includes analyzing how gender and recognition influence the “how” or the manners of givenness of endo.

Using the Epochē to Get Closer to Endo

Exploring the phenomenon of endo “from within” begins for me by temporarily setting aside – or bracketing – what Husserl ([1913] 1962, 91) refers to as the “natural attitude” or “natural standpoint” (*die natürliche Einstellung*). To clarify what this means, I will first describe the characteristics of the natural attitude. The natural attitude is characterized by not being perceived as a specific attitude at all. Husserl uses this term to refer to the ordinary perspective of everyday life, which assumes that the world exists independently of our consciousness and the meanings we assign to it. From the standpoint of the natural attitude, the world is a practical one, where objects are there to be used and possess value characteristics such as beautiful or ugly. We share this world with other people and engage with them as friends or foes. Moreover, our understanding has been shaped by a scientific worldview, leading us to perceive the world as an objective fact world

⁶¹ Notably, Fisher is careful not to construct a simple binary between biomedical condition and illness experience, but instead emphasizes that when it comes to lived embodiment the two aspects are intertwined as mutually conditioning phenomena (Fisher 2014, 35).

that “exists out there,” independently of our conscious experience. Consequently, the scientific worldview is also guided by the natural attitude.

In contrast to this objective fact world, Husserl ([1936] 1978) introduces the concept of the lifeworld (*Lebenswelt*), which pertains to the immediate, everyday world of human experience. While the scientific world relies on objective knowledge that abstracts from how the world initially appears to us, the concept of the lifeworld refers to how the world appears as the always already present and taken-for-granted horizon of our experience. Husserl asserts, “To live is always to live-in-certainty-of-the-world. Waking life is being awake to the world, being constantly and directly ‘conscious’ of the world and of oneself as living *in* the world” (Husserl [1936] 1978, 142). The world is perceived as “simply there” for us in every waking hour, stretching endlessly around us.⁶² As part of this world, we can consciously direct our attention to various objects in space and time. Husserl states (Husserl [1913] 1962, 91–92):

I can let my attention wander from the writing-table I have just seen and observed, through the unseen portion of the room behind my back to the verandah (...) I can shift my standpoint in space and time, look this way and that, turn temporally forwards and backwards.

This realization leads Husserl to make a bold proposal: just as we can willfully direct our attention to different objects, we can also shift our perspective away from the natural attitude. We can suspend the natural attitude by employing a peculiar thought tool called the epochē (Husserl [1913] 1962, 91–92). Husserl compares this shift of attitude to how the mathematician sets aside the natural thesis to adopt a theoretical attitude, viewing the world through the lens of pure numbers. In a similar way, a “theoretical interest shall now be directed exclusively toward the universe of the subjective” (Husserl [1936] 1978, 146). This shift of attention does not imply that one believes the world no longer exists. On this point, Husserl is firm, stating, “I do *not* then *deny* this ‘world,’ as though I were a sophist, *I do not doubt that it is there* as though I were a skeptic” (Husserl [1913] 1962, 100). Instead, the world’s objective existence is simply temporarily placed in “brackets.” It is a suspension (*Aufhebung*) that renders the natural attitude “out of action” for the time being. This suspension allows us to investigate the pre-

⁶² Husserl ([1913] 1962, 91) elaborates: “I am aware of a world, spread out in space endlessly, and in time becoming and become, without end. I am aware of it, that means, first of all, I discover it immediately, intuitively, I experience it. Through sight, touch, hearing, etc., in the different ways of sensory perception, corporal things somehow spatially distributed are *for me simply there*, in a verbal or figurative sense “present,” whether or not I pay them special attention.”

givenness of the lifeworld as such and the hidden bond between the world itself and our perception of it (Husserl [1936] 1978, 151).

Through this process, Husserl suggests that the phenomenologist is freed from the “dogmatism” and “naïveté” of the natural attitude. The first step of Husserl’s epochē involves bracketing the objective sciences (Husserl [1936] 1978, 135). In the context of endo, it means suspending the medical understanding of endometriosis as a diagnosis. This does not imply a lack of faith in, or disregard for, the many achievements of medical science. Instead, it merely means that this aspect is temporarily set aside to allow for a closer examination of endo as a phenomenon. The second step of Husserl’s epochē entails recognizing that the objective sciences are rooted in the lifeworld, which requires its own specific science. Phenomenology serves as this science, focusing on the pre-givenness of the lifeworld as its subject matter. For me, this step involves exploring how endo is given within the lifeworld, drawing from the narratives shared by the interviewees, and investigating how its appearance is shaped by gender and recognition. Through this epochē, according to Husserl, “everything objective is transformed into something subjective” (Husserl [1936] 1978, 178). Thus, phenomenology dismantles the naïveté of the natural attitude while simultaneously reflecting on this naïveté. Eugen Fink (1981, 63) describes this as a methodological step in which “we split ourselves into one who experiences and one who observes that experiencing.” In my case, the focus is not on my own experience but on the experiences of the interviewee. This approach leads to a similar split between their narrated experience and my observation of the givenness of that experience.

This study utilizes Husserl’s epochē as a valuable instrument for analysis. However, some scholars within the field of critical phenomenology, including Lisa Guenther, have raised concerns about its capacity to address the impact of power and history on lived experiences. Guenther contends that the classical phenomenology of Husserl tends to neglect intersubjectivity⁶³ and “would not think of intervening into the transcendental structures of consciousness or even the lifeworld” (2021, 7). In stark contrast, she argues that critical phenomenology aims to actively transform the oppressive structures it examines. Given these divergent objectives, Guenther posits that critical phenomenology must rethink foundational tools and methods, which were originally designed with transcendental structures in mind, such as the phenomenological epochē or reduction.

Against this view, Oksala (2023) convincingly argues that critical phenomenology can be understood as a form of historico-transcendental inquiry, with the

⁶³ Guenther (2013, xiii) argues that the classical phenomenology of Husserl regards “the first-person singular is absolutely prior to intersubjectivity and to the complex textures of social life.” This claim is disputed by both Salamon (2018) and Zahavi (2025).

phenomenological reduction remaining a central, adaptable tool. She cites Beauvoir as a prime illustration of this approach.⁶⁴ This tool can help address what Zahavi (2025, 122) describes as “social practices and beliefs that have become so sedimented that they are often accepted as unquestioned truths, as ontological facts, rather than being recognised for what they are, namely deeply rooted prejudices.” Zahavi raises the question of what remains of phenomenology if critical phenomenology overlooks this central tool, suggesting that a strong focus on lived experience alone is insufficient. Both Oksala (2023) and Zahavi (2021) clarify that their critiques are primarily aimed at phenomenological philosophy, while applied phenomenology may opt to disregard the epochē.

Additionally, scholars like Lanei M. Rodemeyer (2022), Gayle Salamon (2018), and Zahavi (2025) challenge Guenther’s sharp distinction between classical and critical phenomenology, pointing out that Husserl’s later works offer rich discussions of both intersubjectivity and historicity. This study shares a critical ambition with critical phenomenology by exploring themes of gender and justice. It does so by employing recognition theory, which is rooted in the critical theory tradition. However, while critical phenomenology similarly emphasizes power dynamics, I agree with the scholars already mentioned that this does not require abandoning classical phenomenology or overstating the differences between the two. I find Husserl’s epochē particularly useful for suspending the medical perspective on endometriosis and shifting the focus to how endo appears. As mentioned before, critical phenomenology can be seen as extending and radicalizing the reduction, rather than abandoning it (Al-Saji 2017). This approach enables a deeper exploration of the lifeworld and how endo manifests within it, thereby inviting an analysis of power dynamics and experiences of injustice. If the reader accepts my conceptual distinction between “endo” and “endometriosis,” it indicates that they have already started to engage in the epochē alongside me. This distinction already involves moving beyond the natural attitude and directs attention to the lifeworld.

The Essence of Endo

In addition to the epochē, Husserl offers additional concepts to make sense of the hidden bond between the world and perception. He understands our thoughts and actions as structured by intentionality, which means that consciousness is always directed toward objects of thought or experience – it has something “in mind” (Husserl [1913] 1962, 241). Every experience has an intentional

⁶⁴ See also Bonnie Mann (2018b) for a discussion of Beauvoir’s adaptation of the phenomenological reduction.

object, its noema, which is the content of any thought, perception, or judgment. All experiences harbor meaning; they are considered *noetic* (Husserl [1913] 1962, 237). Intentionality can be thought of as this unbreakable relation between the act of thinking, noesis, and what is thought about, noema. In the present study, I consider endo as occupying the position of noema. To reach the “noematic concreteness” (Husserl [1913] 1962, 98) of endo, we need to bracket or disconnect endometriosis as a mere biomedical object and instead focus our attention on *how* it appears. This means focusing on the “lived” aspects of endo – that is, how endo is experienced in the lifeworld. To paraphrase Husserl, this involves asking about the essence of endo: What is endo as such? What essential phases does it harbor in itself in its capacity as noema?

While the term “essence” can be controversial in philosophy, and “essentialism” has been labeled “a cardinal sin in Women’s Studies” (Davis 2014), it is crucial to clarify that, in phenomenology, the concept of essence is seen as an “idea” of a thing rather than something intrinsic to the thing itself. Phenomenology is often defined as the philosophical study of the structures of experience. These structures reveal the essential characteristics of specific phenomena. Grasping essences, therefore, is not about encountering something mysterious or enigmatic. Maurice Natanson (1973, 13–14) further explains:

The word *essence* has a bad name in philosophy partly because ordinary parlance gives it the connotation of mystery. The ‘essence’ of something is an almost occult quality, a hiddenness of things. Husserl takes the opposite task: essences are simply aspects or qualities of objects-as-intended. An older tradition speaks of ‘whatness’ or ‘quiddity’. (...) The phenomenologist believes that essences do not lurk somehow behind or within objects but are the object grasped in its intentional character, grasped *as* being this or that.

For Husserl, perceiving essences is a natural part of our everyday lives. He states, “The truth is that everyone sees ‘ideas,’ ‘essences,’ and sees them, so to speak, continuously; they operate with them in their thinking and they also make judgments about them. It is only that, from their theoretical ‘standpoint,’ people interpret them away.”⁶⁵ For example, when I enter a library, I see “books.” I can only perceive them as “books” by grasping their essence. It is only by understanding what makes a book a book that I can truly identify it as such. Once I recognize the essence of a book, I cannot separate the idea of a book from its essence. In this sense, we interact with essences all the time. Essences are part of

⁶⁵ Edmund Husserl, *Ideen zu einer reinen Phänomenologie und phänomenologischen Philosophie* (Halle, 1913), sec. 22, translated by Dorion Cairns in the article “An Approach to Phenomenology” (Cairns 2013, 13).

our intentionality; they are present in the relationship between ourselves and our everyday world. We think using essences; they are properties of the in-between of subject and world.

Understanding endo as a phenomenon, therefore, entails grasping its essence. My approach to pursuing this essence involves both the epochē and identifying and conceptualizing the generalities and typical features of endo, which I will return to. According to Husserl, “In order to grasp the full noema, we must seize it as we find it in reality (*wirklich*), in the full noematic concreteness in which we are aware of it” (Husserl [1913] 1962, 251). Finding endo “in reality” means exploring it in specific situations and from particular viewpoints. This is why the first-person perspective is important. Since I cannot access the first-person perspective directly, I rely on the interviewees to share accounts of this perspective.

Finding endo in reality also involves disclosing how gender influences lived experiences and exploring the societal and political dimensions of the lifeworld (Fisher 2014, 28). Life with endo is often characterized by its perception as a “women’s disease.” This gendered perception of endo has significant implications for those affected, linked to stigma related to menstruation and the normalization of symptoms. By “gendered,” I mean the social classification of individuals into distinct categories of men and women, along with the associated social statuses and norms. Fisher (2014) emphasizes that the perception of an illness in terms of gender significantly impacts how it is diagnosed, treated, and experienced.

Commitment II. Identifying Generalities and Typical Features of Experience

My interest in the phenomenon of endo extends beyond the experiences as they are described by the interviewees themselves. This brings me to the second phenomenological commitment: to identify generalities and typical features of experience. This step involves transforming narrative descriptions of “messy empirical reality” (Zala et al. 2020) into empirically informed concepts helpful for understanding essential aspects of the interviewees’ experiences. Linda Fisher (2014, 28) describes phenomenology as the capacity to “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.”

Understanding the implications of this structural focus is essential. Lanei Rodemeyer emphasizes that the phenomenological method is not just descriptive; it starts with description to facilitate the “identification of those structures

that must necessarily be in play for those experiences to take place” (Rodemeyer 2022, 96). Phenomenology excels in transitioning from particular, concrete instances to the essential structures that underlie them. It goes beyond mere generalization or thematization – these aspects alone do not distinguish phenomenology. Instead, its uniqueness lies in the “shift from experience to the structures that make that experience, or that type of experience, possible” (Rodemeyer 2022, 96). I use the narratives provided by the interviewees to understand the underlying “possibility and structure of phenomenality” that are intersubjectively accessible (Gallagher and Zahavi 2007, 26; Høffding and Martiny 2016, 543). These structures make endo what it is and appear as recurring traits in the way experience manifests. The task of the phenomenologist is to move beyond individual descriptions to uncover the essential features of experience.

However, while the aim of the study is to deepen the understanding of endo through a phenomenology of its essential features, it does not seek a definitive description or singular truth about the experience of endometriosis, nor does it aim to summarize “women’s experiences” with the condition. Inspired by Fisher, I focus on “generalities and typical features” in the narratives of the interviewees. This terminology serves as an alternative to the “invariant structures” discussed by Husserl and followers (Gallagher and Zahavi 2007, 26; Høffding and Martiny 2016, 543). I find the former expression more accessible to those unfamiliar with phenomenology, and it may help prevent the misinterpretation that all humans or all women universally share the features I identify.

The emphasis on lifeworld and lived experience might suggest that phenomenology mainly focuses on individuals and their specific experiences. However, phenomenology’s structural ambition means that it is not primarily interested in the qualia or purely individual data, nor in the subject as a particular person (Gallagher and Zahavi 2007, 26; Høffding and Martiny 2016, 543). Shaun Gallagher and Zahavi point out that this distinction sets phenomenology apart from psychotherapy and the study of psychological processes. The focus is not solely on individual, idiosyncratic experiences of endo. In line with this structural ambition, I have decided not to use pseudonyms for the interviewees when they are referenced or quoted. Instead, I focus on the content of their narratives and include descriptions of the individuals only when it is relevant for understanding the situations being described. Pseudonyms are typically used to ensure confidentiality, thereby protecting research participants while enabling readers to follow individual stories. However, it has also been suggested that avoiding pseudonyms can enhance participant protection. Saunders et al. (2015) discuss the use of smoke screen strategies, such as assigning different pseudonyms to various extracts from the same participant, to ensure confidentiality. In this study, my decision to forgo pseudonyms enables me to concentrate on generalities and typical features of

experience. The primary objective is to track the phenomenon at the intersubjective level rather than the individual level. This choice underscores my commitment to the phenomenological approach and allows for a sharper focus on the phenomenon itself rather than the specific individual.

I use the descriptions provided by the interviewees as a basis for what Gallagher and Zahavi refer to as “factual variations.” This approach helps uncover the essential aspects that make *endo* what it is. Husserl employed “eidetic variation” to identify essential structures of experience, which involves “using our imagination to strip away the unessential properties of things” (Gallagher and Zahavi 2007, 27). This imaginative approach to discerning essential aspects can be compared to classical philosophical thought experiments. Since I am studying a phenomenon in which I lack personal experience, I rely on the interviewees’ descriptions. This gives me access to rich, detailed accounts of the *endo* experiences that would be difficult for someone without *endo* to imagine. Through factual variation, I can identify recurring patterns that reveal what is general or typical of *endo*, rather than experiences that are purely individual or related to other contexts. In other words, the process of factual variation allows “things to appear as instances of the same phenomenon until one generates a variation that turns the phenomenon into something else” (Gallagher 2012, 308). Thus, factual variation serves as a means to unearth generalities and typical features.

More specifically, to identify, describe, and analyze the generalities and typical features, I started by conducting a thematic analysis (Braun and Clarke 2022).⁶⁶ I segmented the text from each interview transcript into excerpts (or meaning units) of varying lengths, selecting those that offered meaningful insights into the experience and recognition of *endo*. I coded these excerpts with subthemes, which were then grouped into broader themes and overarching main themes. This analytical process did not commence after completing the interviews; it began during the interviews, where I took notes of themes that seemed significant, and it continued throughout the entire process. After transcribing the material, I read each interview multiple times to grasp the overall context. The reading, coding, and analyzing did not follow a linear order. Instead, it can be characterized as a hermeneutical process involving repeatedly revisiting each step of the analysis, moving from parts to the whole. As I identified the main themes, this prompted additional reviews of the transcripts, which led to the discovery of further subthemes in excerpts that I had not initially recognized as interconnected. For instance, it was only in retrospect, after several readings, that subthemes such as “waiting,” “chronic,” “be twice as productive,” “spending the fall

⁶⁶ I use a thematic analysis similar to the phenomenological hermeneutical method as described by Lindseth and Norberg (Lindseth and Norberg 2004, 2022).

in bed,” and “schedule menstruation to weekends” emerged as all related to the main theme of time and temporality.

To demonstrate the typical features of endo experiences, I selected three main themes to form the basis for individual articles. I employed the themes and sub-themes for closer analysis within each article. An example of the analytical structure can be seen in *Table 2* below, which describes the main theme of “Endo Episteme,” in which I conceptualize the epistemic processes of *becoming a knower*, *becoming a patient*, *becoming knowledge*. In the article “Endo Time,” I explore temporal patterns and conceptualize different aspects of time: *waiting time*, *cyclical or chronic time*, and *sedimented time*. In “Endo Politics,” the themes provide a basis for aspects of political mobilization of *developing a fighting spirit*, *becoming a “we,”* and *struggling to be included*. While I do not consider these themes to be exhaustive, they reflect typical features that structure the interviewees’ endo experiences.

<i>Main theme</i>	<i>Theme</i>	<i>Subtheme</i>
Endo Episteme	Becoming a knower	Comparing-with
		Expressive uptake
	Becoming a patient	A pedagogy of pain
		The struggle for diagnosis
	Becoming knowledge	An epistemology of ignorance
		Epistemic activism

Table 2: Themes for Endo Episteme

As may be evident from *Table 2*, the process of identifying, describing, and analyzing themes also entailed theorizing. I not only described and analyzed what the interviewees expressed but also theorized based on my observations. Richard Swedberg (2012) describes theorizing as consisting of the following basic steps: observing, naming and conceptualizing, broadening the concept into a theory, and completing the tentative theory through an explanation. I will use these steps to briefly outline what I mean by theorizing in this context.

Theorizing begins with observation. The term “theory” comes from the Greek noun *theōria* and the verb *theōrein*, which means *to observe*, *to see*, or *to contemplate* (Abend 2008, 180).⁶⁷ The ultimate goal of theorizing is to come up with a

⁶⁷ Heidegger discusses theory in relation to science as follows: “Thus it follows that *theōrein* is *thean horan*, to look attentively on the outward appearance wherein what presences becomes visible and, through such sight – seeing – to linger with it. (...) In *theōreia* transformed into [the Roman] *contemplatio* there comes to the fore the impulse, already prepared in Greek thinking, of a looking-at that

new idea, a process that Charles Sanders Peirce calls abduction, meaning “observing a fact and then professing to say what idea it was that gave rise to that fact” (Peirce 1957, 244; Swedberg 2012).⁶⁸ Peirce distinguishes abduction from other forms of reasoning, like testing hypotheses (deduction) or generalizing from multiple observations (induction). Instead, abduction is rooted in creativity and novelty. It is characterized by “the first starting of a hypothesis and the entertaining of it” (Peirce 1957, 236) – the creative moment of “guessing right” (Swedberg 2012, 18) following an observation. Describing the craft of theorizing can be complex because we cannot summon these new ideas at will. As Max Weber ([1970] 2013, 136) famously stated, and Swedberg also mentions, “ideas occur to us when they please, not when it pleases us.” These kinds of elusive moments of creativity were necessary for the process of naming and conceptualizing the main themes and subthemes for each article. Many ideas emerged while I was engaged in other activities, such as taking a walk or discussing unrelated topics with friends or colleagues.

Swedberg (2012, 20) underscores that observing and naming new phenomena is one of the most crucial tasks in the social sciences. If we fail to do this, these phenomena may slip through our fingers and go unnoticed. He references Durkheim, who proposes that the best way to name new phenomena is to use a term from everyday language. This is what I did when I chose the term “endo” for the main phenomenon. I combined this term with the main theme of each article, resulting in the names and concepts of “endo time,” “endo episteme,” and “endo politics.” The subthemes were named either after concepts I borrowed from existing theories or coined myself, as I found a lack of appropriate concepts to make sense of the interviewees’ experiences. Organizing the themes in relation to one another and ultimately writing the articles meant following the steps Swedberg describes as “broadening the concept into a theory” and “completing the tentative theory through an explanation.” In the articles, I propose explanations in the following sense: these are key aspects that shape the interviewees’ experiences. The themes I discuss are thus not just descriptions of empirical findings; they are concepts that could be applied to analyze other phenomena, including other chronic illnesses. Additionally, the organization of concepts and the resulting approach for understanding processes of recognition could also be useful for studying other phenomena.

sunders and compartmentalizes. A type of encroaching advance by successive interrelated steps toward that which is to be grasped by the eye makes itself normative in knowing.” (Heidegger [1954] 1977, 163–66).

⁶⁸ For a discussion about the relationship between abduction and the phenomenological method, see Jack Reynolds (2023).

Commitment III. Understanding Subjectivity as Irreducible to Objectivity

My third phenomenological commitment emphasizes that subjectivity is fundamentally different from objectivity, which has consequences for key aspects of validity. How can I assess whether the analysis reflects what it is intended to represent – namely, experiences of endometriosis? To evaluate validity, it is crucial to first distinguish between the experience itself and how that experience is described. After clarifying this distinction, I will address the issue of validity in the fourth and final commitment.

The phenomenological interview, like any interview, is a conversation between two conscious individuals who can express their experiences and viewpoints. This type of dialogue facilitates an intersubjective exchange, enabling me to gain a deeper understanding of another person. While intersubjectivity is especially emphasized in phenomenological interviews, it is also an essential part of social research interviews in general since the “objects” studied are actually “subjects” with consciousness, agency, and the ability to produce accounts of themselves and their worlds (Høffding and Martiny 2016, 541).

From a traditional positivist scientific perspective, it is critical to establish correspondence between an experience and its description, similar to how one might consider an object alongside its description. The fundamental question from this viewpoint would be whether the description accurately reflects the actual experience of endometriosis. However, this line of thinking conflates subjectivity with objectivity. It assumes that an experience can be likened to a tangible object, such as a book or an apple, and that the description of an experience can be final or complete in that regard. But unlike objects, experiences cannot be viewed as static “data,” from which we expect complete “reliability” and “reproducibility.” From a phenomenological perspective, experiences are always marked by *form-ness*, or *mineness*, which means they are understood from a subjective first-person perspective (Zahavi 2011).

This commitment aligns with the view of feminist researchers who have long understood research as a subjective, situated, and messy process where claims of absolute objectivity should be approached with a certain degree of skepticism (Haraway 1988; Harding 1986; Skeggs 1995, 195). In her classic study on research interviews, Oakley (1981) critiques the dominant methods of her time that treat the interviewer as a neutral tool for data collection. She challenges the traditional view of interviews as a one-sided exchange, where the interviewer merely gathers information without offering anything in return, thereby reducing the interviewee to a narrow, objectified role as a mere data source. This paradigm of the “proper”

interview reflects values that glorify objectivity, detachment, and hierarchy.⁶⁹ Furthermore, just as interviewees are positioned as mere objects or data-producing instruments, interviewers, from the interviewee's perspective, may similarly be reduced to a functional role, expected to suppress their subjectivity (Oakley 1981, 41). Thus, the ideal interview is envisioned as an object-object relation. Notably, the detached, hierarchical relationship that Oakley describes between interviewer and interviewee resembles the one she observed between doctors and female patients at a London maternity hospital in the 1970s. She recounts this telling scene (1993, 22):

Doctor: [reading case-notes] Ah, I see you've got a boy and a girl.

Patient: No, two girls.

Doctor: Really, are you sure? I thought it said... [checks in case-notes]... Oh no, you're quite right, two girls.

In this study, Oakley identifies a prevalent image in modern obstetrics where women are basically seen as reproductive machines and doctors as the only experts, much like mechanics who are called in when something goes wrong.

Oakley's experiences of interviewing women as a feminist led her to conclude that adhering to these rigid protocols would be morally indefensible, akin to objectifying a "sister" (Oakley 1981, 41). She argues that genuine understanding is best achieved in a non-hierarchical relationship between the interviewer and the interviewee, where the interviewer is willing to invest their personal identity in the relationship (Oakley 1981, 41). Additionally, Oakley highlights that her interviews incorporate elements of friendship and sisterhood stemming from shared experiences of gender subordination. While I agree with Oakley's critique of traditional interview protocols, I remain skeptical about the idea that feminists – presumably women – interviewing women are free from hierarchical or objectifying concerns (see also Thwaites 2017). Oakley herself has acknowledged the validity of this critique.⁷⁰ Nevertheless, I view her initial insights as supportive of

⁶⁹ Oakley provides several examples of this paradigm. One example describes the interview as "an information-gathering tool" (Benney and Hughes 1970, 191). In another instance, the interviewer is characterized as "a combined phonograph and recording system" (Rose 1945, 143). A third states that "the interviewer is really a tool or an instrument" (Goode and Hatt 1952, 185). Moreover, the "respondent," a telling name according to Oakley, is continually framed as passive (Oakley 1981, 35). Finally, she specifically disputes the tendencies of this paradigm by highlighting the numerous times interviewees pose questions of their own during interviews: a total of 878 times.

⁷⁰ In a commentary on her 1981 article, Oakley states: "Many commentators on 'Interviewing women' made important and valid points about the limitations of my argument. They pointed out my failure to acknowledge the complexity of the interview process, especially in relation to the dynamics of power and social divisions between women." (Oakley 2016, 197)

the phenomenological perspective taken here, which posits that subjectivity cannot be reduced to objectivity.

In a phenomenological sense, an experience is not a “thing” that can be easily revisited or collected in a straightforward manner. Experiences have “no fixed diachronic stability, hidden inside the head to be dug up by memory, no Archimedean point of reference” (Høffding and Martiny 2016, 544). They cannot be considered a locked box for which one can find the key and then retrieve old memories. Instead, the act of expressing an experience necessarily alters it. While this act of expression may enrich the experience, it can also flatten it, making it less vibrant (De Boer and Zeiler 2024). This should not be viewed as a drawback but rather as a fundamental aspect of subjective experience.

Commitment IV. Understanding Experience as Embodied, Embedded, and Enacted

In contrast to the objective stance described above, experience should rather be understood as a perspective on the world that changes with every recollection. While experiences often have a stable structure – meaning you typically remember them as *your own* rather than someone else’s – they are still subject to change. This leads to the fourth phenomenological commitment, which emphasizes the embodied, embedded, and enacted foundation of subjectivity.

Experiences are embodied and enacted in a world shared with other experiencing subjects (Zahavi 2015). Therefore, establishing validity in phenomenological interviews involves something other than assessing whether the interviewees’ descriptions are “an accurate representation of their experience as it happened at time T1” (Høffding and Martiny 2016, 544). Instead, such descriptions are understood as new manifestations or forms of the experience. Experiences can take many forms, and describing or reflecting on them should not be seen as distortions of the original experience, but rather as a new “opening up” of it. In this sense, I see the interviewees’ descriptions as manifestations of their experiences, similar to reflections or recollections, but also enacted in the specific interview situation and influenced by my questions and responses. While phenomenology emphasizes the first-person perspective, it is important to note that the knowledge gained from an interview requires adopting a second-person perspective, which involves a reciprocal relation in which each person takes the other as “you” (Zahavi 2015, 93). As a researcher, I enter the interview with specific aims that structure the dialogue. I actively participate in the knowledge production alongside the interviewee. The generation of knowledge is fundamentally inter-

active and reciprocal. Every response from the interviewee shapes my next question, which in turn shapes the following answer. The specific ways in which the dialogue unfolds affect both parties involved. Unspoken factors that are difficult to describe in text, such as emotions, mood, and the interview setting, shape the event in unexpected ways. Both subjects actively and passively contribute to the knowledge production and do so in complex and dynamic ways (Høffding and Martiny 2016, 542). The interviewees' accounts emerge through an "unfolding process that is constituted by loops of memory, reflection, descriptions and questioning" (Høffding and Martiny 2016, 545).

During the interview, validity primarily focuses on obtaining clear and nuanced descriptions rather than on accurate representations of experience. In the subsequent analysis phase, validity is tied to "phenomenological consistency," which refers to the overall account's overall capacity to extend or challenge existing theories of the phenomenon in question (Høffding and Martiny 2016, 545). This is closely related to what Gallagher and Zahavi describe as intersubjective corroboration, which concerns "the degree to which the discovered structures are universal or at least sharable" (Gallagher and Zahavi 2007, 28). In this study, I ensure phenomenological consistency and intersubjective corroboration by identifying common patterns across the accounts from the different interviewees. I then relate these findings to previous research on endometriosis and similar experiences linked to menstruation, gendered chronic illnesses, and chronic pain. I also connect the findings to the themes analyzed in each article, including experiences of temporality, epistemic practices, and political mobilization, as well as relevant philosophical debates.

Together, the four phenomenological commitments guide me in my exploration of endo experiences. I will now turn to the results of this analysis – the phenomenology of how gender dynamics and recognition shape endo experiences – by outlining its three main themes. Each theme is discussed in an individual article, the first focusing on *endo time*, the second on *endo episteme*, and the third on *endo politics*.

SUMMARY OF ARTICLES

Article I. Endo Time: Endometriosis and the Flow of Recognition

Hallström, Ina. (2024b). "Endo Time: Endometriosis and the Flow of Recognition." Hypatia 39 (2): 423–43

The first article, “Endo Time: Endometriosis and the Flow of Recognition,” delves into the intricate relationship between time and gender in endo experiences. Here, I explore how social recognition of endo appears in the lifeworld as a specific orchestration of time, what I call *endo time*. This concept reflects how the lived experiences of endo are shaped by the lengthy waiting time for diagnosis, the condition’s cyclical and chronic nature, and the sedimentation of past time. The article seeks to answer the following questions: What does a temporality of endo look like? How does recognition of endo appear as temporal – what are its paces and rhythms? How can time be considered a question of gender justice?

During the interviews, it became clear that time influenced endo experiences in numerous ways and, conversely, endo influenced the interviewees’ experience of time. It influenced everything from relationships with significant others to education and work life, and hence the interviewees’ plans and projects for the future. Nevertheless, temporality has not been explicitly explored as a theme in relation to endo experiences. Feminist phenomenology has addressed many related topics, such as the lived experience of temporality, menstruation and female embodiment, and illness and pain – but has not specifically focused on endo. Due to its connection to feminized pain and menstrual flow on one hand and social recognition and responses on the other, endo presents an illustrative case, with broader resonance, for exploring the relationship between gender, recognition, and lived time.

I argue that lived time can be studied by approaching becoming as a dynamic process or *flow of recognition*, which creates certain temporal patterns in the lifeworld that tend to affect both social relations and self-relations over time. To

thematize the temporality of recognition, I draw on feminist theory and phenomenology, specifically the notion of gender as “lived time” (Burke 2018), alongside concepts like crip time and queer temporality. I return to Husserl’s understanding of internal time-consciousness to argue that concepts such as becoming do not necessarily entail the optimism sometimes critiqued in feminist discussions of temporality. Instead, becoming encompasses how consciousness constitutes temporal experiences; without this process, we would not perceive time as going slowly or stopping while at the same time knowing that such experiences differ from objective “clock” time. Husserl offers a comprehensive account of the complexities involved in temporal experiences.

Based on the interviews, I proceed to identify three themes or temporal patterns that characterize *endo time*: waiting time (I), cyclical or chronic time (II), and sedimented time (III). *Waiting time* refers to the prolonged delay in obtaining a diagnosis and treatment, which negatively affects the interviewees’ outlook on the future. One interviewee experienced symptoms from the age of 12 but was not diagnosed until 28 years later. Many had sought help for menstrual pain since adolescence, only to be told by medical professionals that “menstruation does hurt” and that “pain is normal.” One interviewee describes how “everything melted together” as she spent the entire fall in bed. It was only after receiving treatment that she felt capable of resuming her studies and envisioning a future again. Similar interviewee experiences echo both the “passive present” Burke (2018) finds in Beauvoir and the “inhibited intentionality” described by Young’s (2005b). Ultimately, the consequence of this “confinement” to the present is the loss of a sense of the future, preventing the interviewees from shaping their own life paths and pursuing personal goals. Some interviewees also participated in political mobilization against the delays in diagnosis, with Sweden’s Worldwide EndoMarch 2017 highlighting the slogan: “Eight years is not OK.” These initiatives represent a struggle for recognition where *endo time* is explicitly politicized and *waiting time* constitutes a prime target.

Cyclical or chronic time refer to the temporality of symptoms. The cyclical pain associated with menstruation is often seen as a natural part of “womanhood” and is *normalized*. This normalization led several interviewees to form a negative self-relation, perceiving themselves as “weaker” than others or “lazy.” In this context, receiving a diagnosis becomes vital, acting as proof that they are not “crazy.” Chronic or unpredictable pain, however, is often unintelligible and *stigmatized*. The interviewees report that talking about such pain is challenging or “scary,” as others may see those affected as “difficult” or “whining.” Moreover, chronic pain disrupts the ability to meet social expectations related to time and productivity, causing what I call temporal stigma. Ultimately, this creates a dilemma: cyclical

pain is seen as too normal to be understood as pathological, while chronic pain is viewed as too abnormal to fit conventional life narratives.

Finally, *sedimented time* reflects the relationships between the passage of time and the body's concrete materiality in two key ways. First, the interviewees discuss how the symptom of heavy flow disrupts cultural rhythms and social habits, such as the "normal" frequency of bathroom visits or "risky" situations like sleepovers. The fear of leaving stains involves the management of both time and identity, as stains elicit shame because of their tendency to mark the wearer as dirty, messy, or poor. Second, prolonged waiting for diagnosis allows endometrial tissue to grow and spread to other organs, increasing the risk of chronic pain and infertility. Many interviewees feel their conditions worsened due to these delays and express a loss of trust in doctors and the healthcare system. This loss of trust highlights how fragile the recognition of patients' experiences can be and illustrates how perceived injustices motivate calls for change.

In conclusion, through the notion of *endo time*, I contribute to the existing research by thematizing how experiences of endo and processes of recognition can be conceptualized in temporal terms, creating a unique orchestration of time. The *endo time* experienced by the interviewees results from social recognition entangled with processes of the body, such as menstrual flow. I argue for a phenomenological understanding of lived time, challenging the assumption that concepts like "becoming" imply optimism. This is important because it allows description of the negative consequences of inaction in the face of a progressive illness such as endo. As a form of lived time, *endo time* should not be understood as external to the body; it flows through it and is sedimented over time. The concept aims to capture the complexity involved in experiences of time – and the ways in which different levels of time coexist and are interrelated. Waiting, for instance, would not be experienced as waiting if we did not simultaneously experience time as something that does not pause while we wait. These experiences are related to clock time, such as the years of delayed diagnosis. They are related to waiting, temporal norms, and temporal stigma. But rather than understanding experiences as mere moments in objective time, I suggest we understand them as lived, as sedimented, and as constitutive of who and what we become.

Article II. Endo Episteme: Epistemic Injustice and the Misrecognition of Endometriosis

Hallström, Ina. (2024a) "Endo Episteme: Epistemic Injustice and the Misrecognition of Endometriosis." *Feminist Philosophy Quarterly* 10 (4).

In the second article, "Endo Episteme: Epistemic Injustice and the Misrecognition of Endometriosis," I explore how individuals with endometriosis progress from experiencing pain to knowing that they have this specific condition. I analyze how knowledge about endo appears and takes on meaning in the lifeworld. During my analysis of the interviews, knowledge emerged as a main theme in how endo was experienced and recognized. Nevertheless, research on the connection between endo and knowledge is limited. In particular, the everyday epistemic practices involved in the diagnostic journey have not been made a central concern, nor has their relation to processes of recognition.

The article aims to address the following questions: How do the interviewees come to know endo? How is knowledge gained, negotiated, or lost? What are the implications for the interviewees' relations to self? To explore these questions, I present a phenomenology of the "lived" (*erlebt*) epistemic practices involved in the journey toward knowledge about endo. These practices constitute what I call *endo episteme*. I use a theoretical framework that combines Honneth's theory of recognition with Miranda Fricker's (2007, vii) notion of epistemic injustice, which examines "those human practices through which knowledge is gained, or indeed lost." Furthermore, I connect this analysis to contemporary discussions on integrating the concepts of epistemic injustice and recognition, particularly those appearing in a special issue of *Feminist Philosophy Quarterly*, the journal in which my article is also published. Through the analysis of *endo episteme*, I identify and conceptualize a number of epistemic practices in the lifeworld of the interviewees. These practices shape the crucial epistemic processes of becoming a knower (I), becoming a patient (II), and becoming knowledge (III) in relation to endo.

The process of *becoming a knower* concerns "epistemic support," which involves support within close relationships of love and friendship. Having our individual needs met in this context is crucial to fostering a sense of epistemic agency and self-confidence. I identify two prominent epistemic practices that appear essential for becoming a knower. The first is "comparing-with," which refers to how the interviewees compare their own experiences to those of people in their surroundings to gain a deeper understanding of these experiences. This helps them determine whether the pain they experience is normal or pathological. The second epistemic practice is "expressive uptake," which entails the interviewees receiving emotional support from family or friends when they describe their struggle with symptoms, thereby allowing them to articulate and understand their

emotions. Both of these practices serve as significant sources of epistemic support and enhance epistemic agency, making it easier to become a knower in relation to endo symptoms and to take the next step and seek healthcare.

Becoming a patient reflects “epistemic respect,” which concerns our status as legal and moral equals. The World Health Organization affirms that health is a universal human right. However, the interviewees’ experiences indicate that gender bias undermines this right. I outline two key epistemic practices that shape the diagnostic journey. The first practice, “the pedagogy of pain,” encompasses the common belief that menstrual pain is normal. This notion is so prevalent in the interviews that it resembles a mantra, teaching young individuals how they should react to their pain by enduring it. Over time, this practice creates an expectation to ignore pain, and those who do not conform risk credibility downgrading, for example by being labeled as “hysterics” or “hypochondriacs.” The second practice I term “the struggle for diagnosis,” which refers to the efforts and strategies the interviewees use to obtain a diagnosis and be recognized as patients. These involve consulting multiple doctors, often upon the recommendation of other patients, or even “bringing a man” to the doctor’s office to ensure they are taken seriously. The interviewees often state that obtaining a diagnosis is crucial for validating that they are not “insane” and that their symptoms are not simply “all in their head.”

Finally, *becoming knowledge* involves “epistemic esteem,” which concerns the status of endo experience in shared hermeneutical resources and whether society recognizes and values the illness and lived reality of the interviewees. Fricker (2018, 3), notes that 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 if experiences are shared with an in-group, they may not be rendered intelligible in the wider society because of a structural “under-contribution” to shared hermeneutical resources. I identify two main epistemic practices that are crucial for becoming knowledge. The first, “the epistemology of ignorance,” refers to the widespread lack of medical knowledge related to endometriosis. The interviewees note that the absence of medical knowledge results in low status for the disease, leading to symptoms being seen as “weird” or being categorized using “trashcan diagnoses.” The second practice, “epistemic activism,” reflects the efforts of the interviewees to address this issue through political mobilization, such as advocating for national guidelines for endometriosis care.

In conclusion, this article contributes by thematizing the everyday epistemic practices in the diagnostic journey, which prior studies overlook. Understanding the epistemic obstacles from a patient perspective sheds light on the reasons behind delays in diagnosis and treatment. It is critical to resolve these delays to

improve patients' quality of life. This is particularly important as individuals who are ill may be especially susceptible to epistemic injustice. The article shows that the practices of comparing-with and expressive uptake are essential for gaining knowledge. The pedagogy of pain and the epistemology of ignorance show how knowledge is lost rather than gained, leading to missed opportunities for learning. The struggle for diagnosis and epistemic activism both reflect attempts to negotiate knowledge to overcome ignorance and other epistemic obstacles. By focusing on recognition, we can see how these experiences affect the interviewees' relations to self. A lack of epistemic support can reduce their epistemic self-confidence and agency. When they are not recognized as patients, this can diminish their sense of sanity. Overall, these examples illustrate how epistemic injustice affects both the knowledge and the knower's self-relation.

Article III. Endo Politics: How Identity Obstructs the Recognition of Endometriosis

Hallström, Ina. (2026) "Endo Politics: How Identity Obstructs the Recognition of Endometriosis" [Manuscript submitted for publication]

In the third article, "Endo Politics: How Identity Obstructs the Recognition of Endometriosis," I describe and analyze how the interviewee's quest for diagnosis and treatment leads to a struggle for recognition, which I call *endo politics*. A main theme that emerged during the interviews was mobilizing to have the condition diagnosed and recognized, along with issues connected to identity. It became clear that the way endo patients were categorized in terms of gender, race, ethnicity, and dis/ability shaped the illness experience and the interviewees' struggle for change. While prior research has also explored some aspects of endo and social movements, such as endo support groups and online activism, these studies have not thematized how first-person endo experiences spark social movements and how identity impacts the struggles.

I contribute to this area by providing a phenomenology of *endo politics*. To tease out the relationship between recognition and identity, I use a recent debate between Axel Honneth and Judith Butler on theorizing recognition. In the debate, Honneth (2021b) proposes an analytical distinction between two different understandings of recognition. Firstly, "cognitive" or epistemic recognition emphasizes intelligibility and social categorization. Secondly, "normative" recognition concerns recognition that grants someone a normative status. The latter is, for Honneth, the proper meaning of the Hegelian notion of recognition. In contrast,

Butler suggests an alternative distinction where “recognizability” precedes “recognition” and refers to historical schemas of intelligibility that prepare subjects for recognition. The article aims to address the following questions: What characterizes this “lived” politics of endo? How are identity and recognition related to each other in this case? Endo is a gendered condition and feminist concern, but does this imply that gender identity is the “object” for which interviewees seek recognition? To address these questions, I identify three primary themes that illustrate how *endo politics* appears in the lifeworld of the interviewees: developing a fighting spirit (I), becoming a “we” (II), and struggling to be included (III).

Developing a fighting spirit concerns how the interviewees start regarding their individual struggle to obtain a diagnosis and treatment as an instance of injustice. In this struggle, identity is not the “object” for which they seek recognition; instead, the focus is on their needs and categorizing these needs in terms of diagnosis and disease. However, identity often gets in the way of recognition of their needs. As one interviewee states, “no one wants to pay for women’s illnesses.” The interviewees describe several instances where either gender or age works against them in their pursuit of diagnosis, it affects their recognizability to use Butler’s term. In connection to this realization, they also describe a personal transformation where they go from accepting defeat to starting to stand their ground and becoming more assertive and demanding. This heightened sense of agency and determination is what I describe as developing a “fighting spirit.” As the interviewees perceive identity as getting in the way of recognition and developing a fighting spirit, they often expand their awareness beyond individual experience. They start to view the personal as political, and many feel an urge to find others. Developing a fighting spirit can be understood as becoming part of what social movements research calls the “protest potential.”

Becoming a “we” refers to the formation of a collective identity together with other patients. Some interviewees mention joining the Swedish Endometriosis Association. They also describe participating in activism, such as protest marches advocating for national guidelines for endometriosis care. Some join endo support groups on social media to share their experiences and connect with others. Many interviewees express a strong sense of “we” based on their connection with the endo community. One interviewee describes the feeling, “It’s like, it’s *us* (...) endo warriors, endo sisters – we are like a sisterhood, we try to... it’s like us against the world.” I link this perception of a “we” to what Husserl described as we-intentionality or *Gemeingeist*. These experiences reflect the formation of group identity, which Young (2011, 44) defines as an affinity to “a certain social status, the common history that status produces, and self-identification.” Becoming a

“we” revolutionizes subjectivity by creating a communal spirit based on the perceived injustice of that position.

However, while labels like “endo sisters” can foster unity around common goals, they can also be perceived as excluding. *Struggling to be included* refers to how the interviewees struggle to move beyond or expand social categories that tend to exclude them. For instance, one interviewee highlights the importance of addressing the power aspect connected to the neglect of women’s illnesses while simultaneously avoiding gender-exclusive language, and suggests using terms like “endo siblings” instead of “endo sisters.” Other interviewees highlight how invisible illnesses like endo often go unrecognized in relation to disability rights, such as the right to use accessible seating in public transport. An interviewee with a Muslim background shares her challenges discussing endometriosis within her community and notes that other Muslim girls contact her with questions about it. This can be seen as creating an alternative we-community, aligning with prior research indicating that sustained activism is easier when a person’s different life spheres interconnect. Taken together, the interviewees describe how various identity categories – such as gender, race, ethnicity, or invisible dis/ability – can obstruct recognition and make it difficult to assume the sick role. The formation of a “we” fosters collective action and shifts the struggle from a personal level to a political one. However, once a collective “we” is established, the risk of exclusion re-emerges, alongside the need to revolutionize subjectivity. The struggle to be included complicates the notion of “we” and the role of identity within the movement. For instance, the struggle may involve challenging language use, expanding available categories, or creating alternative forms of “we.”

In relation to prior research, this article contributes by thematizing how first-person endo experiences ignite social movements and the role of identity in these struggles. To gain a deeper understanding of these experiences, I suggest using both Honneth’s and Butler’s perspectives on recognition, but they should not be conflated. We need to differentiate not only their views on recognition but also their concepts of identity. Butler’s perspective emphasizes categorization, which primarily addresses group identity, whereas Honneth’s approach focuses on “personifying” recognition through support, respect, and esteem, which ultimately promotes a positive self-relation. By integrating elements from both Butler and Honneth, I can refine the assertion that “identity obstructs recognition” into a clearer conclusion: while identity is not the object of recognition, social identities can obstruct acts of personifying recognition, an obstruction that the interviewees perceive as an inadequate concern for their needs and rights. The analysis demonstrates how group identities can be taken up in various ways, contested, and transformed. I view this as an ongoing process – a dialectic – between an individual and a collective spirit that never truly ends.

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The three main themes of “endo time,” “endo episteme,” and “endo politics” illustrate how endo typically manifests in the lives of the interviewees, shaped by gender dynamics and recognition processes. Analyzing these aspects of lived time, epistemic practices, and politics, I have identified generalities and typical features of the gendered recognition of endo. Experiences of enduring *waiting time*, encountering *a pedagogy of pain*, or *struggling to be included* are often described as negatively affecting the interviewees’ self-confidence, self-respect, and self-esteem. I see these instances of injustice and disrespect as fueling the *struggles for diagnosis* and fostering what I call *a fighting spirit*. Collectively, these themes highlight typical features of society’s way of recognizing endo and what it is like to live with endometriosis in Sweden.

CONCLUDING DISCUSSION

What Have We Learned?

When I understood that so many people have this without knowing it, and that you don't get any help, and everything else that comes with this illness... I think that's when it became important for me to take it to the next level and try to get more involved. (...)

I think I quickly connected it to something bigger, to something collective as well, something related to structures (Interview no. 11).

Endometriosis is a common and painful condition affecting millions worldwide. In recent years, it has also become a site of gender justice struggles. In this study, I have provided a phenomenological analysis of this often-overlooked condition, viewing patients' experiences and calls for change as exemplifying a contemporary struggle for recognition. The case of endometriosis represents both a new expression as well as a continuation of earlier feminist and health-related social movements, advocating for rights, equality, access, and improved scientific knowledge, often rooted in lived experience (Brown et al. 2004). The individuals interviewed in this study represent the last generation of endometriosis patients before Sweden introduced national guidelines for endometriosis care, reforms with potential to improve the lives of approximately 250,000 affected people in the country, and particularly future generations (National Board of Health and Welfare 2018). Documenting their stories is important for understanding the factors that led to recent reforms and for supporting ongoing efforts to improve conditions for those living with endometriosis.

The central aim of this research has been to deepen the understanding of how gender and recognition shape lived experiences of endometriosis. Specifically, I set out to explore how gender dynamics and recognition processes within the interviewees' lifeworlds shape their experiences of living with endometriosis (endo), and how these experiences affect their self-relation and motivations to change their personal and collective circumstances. I address this issue by identifying generalities and typical features in the interview narratives and by creating empirically informed concepts to develop more nuanced theories on endometri-

osis, gender, and recognition, and how they interrelate. My goal has been to thematize experiences in ways that contribute to both empirical knowledge and philosophical theorizing. By approaching endometriosis as the phenomenon of “endo,” I theorized three typical modes of its appearance in the lifeworld: *endo time*, *endo episteme*, and *endo politics*. To highlight the study’s contributions, I will revisit the core characteristics of qualitative research described by Aspers and Corte (2019). They emphasize the capacity of qualitative research to generate *new knowledge* and *deeper insights* by making *new distinctions*.

This study contributes *new knowledge* by providing detailed descriptions of the complex experiences of living with endometriosis, generated through in-depth interviews with 15 individuals diagnosed with the condition. These first-person accounts fill a significant gap in the literature, especially given the scarcity of such narratives in Sweden. This empirical foundation enabled me to address the first research question regarding how gender dynamics and recognition processes shape the interviewees’ endo experiences. First, by offering detailed, nuanced descriptions of the interviewees’ experiences. Second, through an analysis focused on how gender dynamics and recognition processes shape these experiences, emphasizing the interconnectedness of endometriosis, gender, and recognition. The study contributes to international research on endometriosis, as the theme of recognition has not been a primary focus, despite documented challenges in understanding and acknowledging symptoms and in obtaining medical recognition through diagnosis. By thematizing recognition informed by first-person accounts, it adds new knowledge that clarifies how delays and obstacles in diagnosis and treatment manifest concretely in lived reality. It also demonstrates how such experiences can influence individuals’ self-relation and their motivation to change their personal and collective circumstances. I will revisit these points when discussing my contribution to endometriosis research.

This study also provides *deeper insights* and a deeper understanding of the interviewees’ experiences through an empirically informed phenomenology that draws on and thematizes the material generated in the interviews. Inspired by Husserl’s epochē, I concentrated on the phenomenon of *endo* to describe and comprehend how it manifests in the interviewees’ lifeworlds, rather than approaching it as the medical object of endometriosis. The phenomenon of endo served as my lens for exploring three interconnected themes that have interested me from the start: gender, pain, and social recognition – or, in this specific context, gender, endometriosis, and recognition. Together, these three elements *constitute* endo and make certain endometriosis experiences possible. Drawing on the interview narratives, I identified, described, and analyzed their generalities and typical features. This focus on the structural aspects of experiences, and on what makes experiences possible, rather than on purely individual data, is a distinctive

characteristic of phenomenological philosophy, and sets this study apart from other forms of qualitative empirical research. Through this process, I identified three main themes that illustrate how endo typically manifests in the interviewees' lives – shaped by gender dynamics and recognition processes. These themes demonstrate not only *that* recognition matters, but also *how* it matters and manifests in lived reality.

The next stage of theorizing involved creating *new distinctions* based on the identified themes. I introduced the empirically informed concepts of *endo time*, *endo episteme*, and *endo politics* to describe how these manifestations of lived time, epistemic practices, and politics are characteristic of the interviewees' endo experiences. *Endo time* illustrates how the gendered recognition of endo appears as a specific orchestration of lived time. This lived time is marked by what I call “waiting time,” which provides language corresponding to the slogan “Eight years is not OK” and highlights the implications of this temporal experience for the interviewees' future outlooks. It is also marked by the temporality of symptoms and lived as “cyclical or chronic time” and ultimately “sedimented time,” since lived time is always also embodied and material. *Endo episteme* demonstrates how the gendered recognition of endo manifests as certain lived epistemic practices, which I describe through the processes of “becoming a knower,” “becoming a patient,” and “becoming knowledge.” These can be understood as various processes that shape the interviewees' journey toward knowledge of their condition. *Endo politics*, in turn, shows how the gendered recognition of endo manifests as moments of lived politics, which I call “developing a fighting spirit,” “becoming a ‘we,’” and “struggling to be included.” This form of lived politics continues a long-standing feminist tradition of turning personal experiences into political action to challenge unjust conditions. Together, these themes and concepts capture key aspects of how endo appears in the interviewees' lifeworlds.

In summary, my exploration of the gendered recognition of endo has revealed three fundamental themes that illustrate how the condition typically manifests in the interviewees' lives. By developing empirically informed concepts that reflect lived experiences of gender dynamics, I demonstrate how a focus on the theme of recognition can enrich analyses of gender, and how gender studies, in turn, can enrich recognition theory by theorizing the interplay between gender dynamics and various forms of recognition. In the following, I want to highlight key contributions to relevant fields.

Endometriosis Research and Policy

This study identifies three key themes that warrant greater attention in endometriosis research and policy. Since it relies on 15 in-depth interviews, its results are

not intended to be broadly generalizable, unlike those from quantitative research. My goal was to gain a deeper, richer understanding of this specific phenomenon. While this analysis does not indicate how frequently these experiences occur in a larger population or how they compare in significance to issues not present in this sample, the insights can inform further research, including quantitative studies. Most importantly, they can benefit everyone living with endometriosis or interacting with affected individuals, as well as those involved in relevant decision-making. Beyond patients, family, and friends, these people include teachers, school nurses, healthcare professionals, government agencies, and policymakers.

While some aspects of the themes of *endo time*, *endo episteme*, and *endo politics* have been addressed in earlier research, none have been explicitly spotlighted, thematized, or theorized, making this thematization a significant contribution of the current study. For example, although “delayed diagnosis” has been identified as a critical issue, prior research on endometriosis has not explored temporality per se or the lived experience of time in depth. This contrasts with the phenomenological tradition, which has long detailed the temporal dimensions of experience. In my discussion of “endo time,” I therefore revisit issues raised in prior research, while also generating new accounts that thematize and demonstrate how recognition can possess a specifically temporal dimension. *Endo time* emphasizes not only the long waiting times for diagnosis but also the subjective, existential, and social aspects of such experiences. “Waiting time” refers not only to delays in diagnosis per se but also to the emotional impact of waiting, such as feelings of abandonment and adverse effects on future outlooks, thereby deepening understanding by adding an existential layer to the significance of timely diagnosis. “Cyclical or chronic time” reveals how the temporality of symptoms garners different kinds of recognition, prompting a critical examination of gendered norms and the normalization of symptoms linked to menstrual cyclicity, and the unintelligibility that the interviewees describe regarding their chronic symptoms. “Sedimented time” underscores the risks of delaying treatment, as allowing time to pass enables tissue growth, potentially worsening symptoms, increasing the risk of chronic pain and infertility, and is often perceived by the interviewees as a reflection of their worthlessness. An awareness of the negative impact such experiences have on the interviewees’ self-confidence, self-respect, and self-esteem points to the ethical dimensions and responsibilities involved in everyday interactions with those affected.

Similarly, regarding epistemic practices, despite documented and widespread knowledge gaps, epistemic practices have not previously been thematized or theorized in a structured manner. In the discussion of “endo episteme,” I introduce new accounts while also revisiting the normalization of symptoms and the lack

of knowledge patients face, to demonstrate how recognition is expressed in everyday epistemic practices. This theme demonstrates that epistemic practices are crucial for addressing delays in diagnosis and treatment. I emphasize the significance of receiving epistemic support and expressive uptake from family and friends, as these are essential for self-confidence, making sense of one's experiences, and taking the next step in seeking care. When such support is absent, it becomes even more important for institutions such as schools and healthcare providers to offer epistemic support and respect beyond mere information. The interviews show that seeking medical help often involves an unnecessarily complicated "struggle for diagnosis," which illustrates the efforts and strategies the interviewees use to be taken seriously. The interviewees also report a negative impact on their self-relation linked to how medical professionals treated them; they started to question themselves and even their own sanity. Since a diagnosis is a form of knowledge classification with normative implications, removing unjustified barriers to recognition as a patient – the legitimate subject entitled to medical care – is vital. This theme also underscores the need to disseminate and expand current medical knowledge, which depends on research funding, particularly since no cure for endometriosis currently exists. Furthermore, it points to the importance of changing social norms and biases related to menstruation and pain, a challenging but necessary task, as missed opportunities for knowledge can result in years of delayed diagnosis and treatment. Ultimately, we must collectively unlearn what I call the "pedagogy of pain," which will involve educating young people to prevent future generations from normalizing menstrual pain.

In relation to "endo politics," I describe how personal experiences of the difficulties in obtaining a diagnosis and treatment foster a struggle for recognition and political mobilization – a topic that has remained unexplored in the literature. The theme of "endo politics" also addresses the existential dimension, illustrating how the interviewees perceive the lack of medical recognition and care as a gender-specific injustice. This perceived injustice sparks in them what I describe as a "fighting spirit," and a desire to unite with others, of "becoming a 'we.'" This reflects the activism seen in other feminist and health movements, like the breast cancer movement. The interviewees also describe how social identities can obstruct proper recognition. I highlight challenges related to gender, like the classification of endo as a "women's disease," along with issues tied to non-binary gender identities, ethnic minority status, and invisible disabilities.

The empirically informed concepts I have developed not only deepen the understanding of endometriosis experiences and add to existing endometriosis research but also provide a basis for further analysis. The value of developing concepts in this way is illustrated by the fact that an article on endometriosis has already embraced the notion of "endo time," expanding on the framework by

incorporating, beyond the forms of time I identify (waiting time, cyclical or chronic time, and sedimented time) accounts of *acuteness*, where the condition worsens to the point of risking life and requiring urgent treatment (Oikkonen and Helosvuori 2024).

Exploring endometriosis has made me aware of the need for further research. The present study was based on interviews conducted before Sweden introduced national endometriosis care guidelines in 2018. Conducting another similar study could show whether patient experiences have changed post-implementation. There is also a significant need to examine children's experiences with endometriosis, particularly in the Swedish context, where this is lacking. The medical classification of endometriosis mainly places it under gynecology, and young people in Sweden are generally advised to visit youth centers instead of gynecology clinics. Although endometriosis often begins with the first menstruation, it is typically seen as a women's disease, a view that may exclude younger patients. Encouragingly, in 2023, a new educational program and website focused on endometriosis in children and teens was launched in Sweden, promoting early detection and treatment (LÖF 2023). In addition to age, it is crucial to deepen understanding of how gender intersects with factors like race, ethnicity, dis/ability, and LGBTQ+ identities in endometriosis experiences. While this study addresses these aspects only briefly, it indicates their importance and the need for systematic research.

Gender Studies and Feminist Phenomenology of the Body and Illness

By examining endo through the lens of recognition, I demonstrate how the Hegelian theme of recognition can be productively used in gender studies and feminist phenomenology, extending beyond the key contributions of Beauvoir and Butler. Honneth's recognition theory, which emphasizes various forms of recognition, is particularly useful for analyzing phenomena such as endo because it links individual self-relations, social relations such as gender, and the forces driving social change. By emphasizing everyday experiences of injustice and disrespect, the concept of recognition reveals the motivating factors behind social struggles, of which the feminist movement is a key example. By integrating recognition theory with phenomenology to focus on gender dynamics, I develop a feminist phenomenology of recognition. This approach holds significant promise for examining phenomena beyond endo, and particularly for addressing justice issues by beginning with everyday experiences. Similarly, the empirically informed concepts I have developed to capture the interplay between gender dynamics and recognition processes may also have broader applications in feminist

and gender studies. They could be helpful in addressing other gender justice issues related to temporality, epistemic practices, politics, or other themes beyond illness experiences.

Moreover, each article not only introduces new empirically informed concepts but also engages with philosophical debates relevant to feminist theory. “Endo Time” discusses gender as lived time and challenges the sometimes-suggested separation between lived experience and philosophies of becoming by tracing Beauvoir’s use of becoming to Husserl’s phenomenology. “Endo Episteme” discusses and merges Miranda Fricker’s idea of epistemic injustice and Honneth’s recognition theory. Lastly, “Endo Politics” interrogates and combines Butler’s notion of recognizability and Honneth’s concept of recognition. By concluding that although identity is not the object of recognition, social identities can obstruct acts of personifying recognition, I contribute to ongoing debates about identity politics through the case of endo. These debates are highly relevant for gender analysis and feminist theory. Ultimately, this research demonstrates how empirical qualitative research can enrich feminist philosophical discussions.

The contributions to endometriosis research mentioned above are also relevant here, as this study details the connections between endometriosis, gender, and recognition, thus aligning with the focus on social categorization and gendered embodiment in gender studies and feminist phenomenology. Through this study, I present a phenomenology of a previously underexplored phenomenon. This inclusion expands on previous descriptions of lived experiences within feminist phenomenology, covering topics such as menstruation, pregnancy, breasts (Beauvoir [1949] 1956; I. M. Young 2005b; Heinämaa 2014), childbirth (Trigg 2021; Oksala 2004), illness and pain (Käll 2012; Fisher 2014; Käll and Zeiler 2014), breast cancer (De Boer et al. 2019), embodiment in medical practice (Slatman 2014), body shame (Dolezal 2015b, 2015a), and aging and disability (Weiss 2014, 2017). Thereby, I add accounts of a gendered chronic illness that shares affinities with other similar conditions that predominantly affect women. A recent study found that the US National Institutes of Health, the world’s largest public funder of biomedical research, allocates a disproportionately higher share of its resources to diseases that mainly affect men, at the expense of those that predominantly affect women (Mirin 2021).⁷¹ Endometriosis is explicitly mentioned as one of the most underfunded female-dominated illnesses. Endometriosis thus remains a paradigmatic case situated at the intersection of gender, health, and justice, closely linked to other feminist concerns about menstrual

⁷¹ The study found that funding patterns favor males in nearly three-quarters of cases where a disease primarily affects one gender, either because the disease affects more women and is underfunded (relative to its burden) or because the disease affects more men and is overfunded (Mirin 2021).

stigma, gender equality in health, and the hysterization of female patients (Jones 2015; Seear 2009c; Johnston-Robledo and Chrisler 2013). There is also a significant need for further research on gender and health to enhance both empirical and theoretical understanding. Several other conditions that mainly impact women warrant greater attention, including premenstrual syndrome (PMS), premenstrual dysphoric disorder (PMDD), fibromyalgia, myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS), long COVID, polycystic ovary syndrome (PCOS), and adenomyosis, which resembles endometriosis but involves tissue growing into the muscular wall of the uterus rather than outside it (Gibson-Helm et al. 2016; Santulli et al. 2025; Ganesh et al. 2025). Combining recognition theory and feminist phenomenology could provide a strong basis for further research into the lived experiences of such conditions.

Recognition Theory and Critical Theory

By exploring endometriosis through the lens of recognition, I have taken a bottom-up approach to theorizing recognition, starting from the “messy empirical reality” and the non-ideal conditions that individuals with endometriosis face. This methodology of combining phenomenology and recognition philosophy with empirical research not only has the potential to deepen our understanding of gender relations but also aligns with the spirit of critical theory. In following this approach, I demonstrate how gender studies can contribute to recognition theory by theorizing the interplay between gender dynamics and various forms of recognition. This adds “the specificity needed” to recognition theory, which Young (2007, 193) calls for to enable effective feminist critique. Additionally, I show how particular dimensions of recognition can be thematized and analyzed separately by introducing the concepts of “endo time,” “endo episteme,” and “endo politics.” This approach could be extended to themes beyond time, epistemic practices, and politics. This study represents only an initial step in exploring how research on gender dynamics can enrich recognition theory. I see significant potential in developing recognition theory in this direction and further expanding the framework of a feminist phenomenology of recognition.

I conclude that the methodology used in this study allows us to better “comprehend both the structures of social domination *and* the social resources for its practical overcoming” (Honneth 1993, xiv) in the context of this particular gendered chronic illness. As Miranda Fricker (2018, 4) rightly observes, “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.” By investigating experiences of injustice

and disrespect, we can uncover crucial insights into their positive counterparts and identify ways to realize them. *Recognizing Endo*, in this sense, makes a modest but meaningful contribution to “the self-clarification of the struggles and wishes of the age” (Marx 1843). As a result, it also offers an example of how critical theory can be realized today.

Where Do We Go From Here?

At the outset of this study, I observed that endometriosis was gaining increased visibility in the media, on social media platforms, and through personal testimonies. It seemed poised to enter mainstream public awareness. Several interviewees also mention this growing visibility during our meetings, and some describe taking part in events related to Endometriosis Awareness Month, held annually in March. Established in 1993 as Endometriosis Awareness Week by the Endometriosis Association (2025), it has since evolved into a global observance. A brief international overview indicates that the rise in public recognition of endometriosis is still in progress. Mentions of “endometriosis” in books and printed sources peaked in 2014 – a year frequently identified as pivotal for feminism.⁷² Interest then surged again, reaching an all-time high in 2021, with data currently available through 2022.⁷³ The search term “endometriosis” saw its highest interest in October 2025 since *Google Trends* (2025b) tracking started in 2004.⁷⁴ In Sweden, the 2018 national guidelines for endometriosis care have been followed by further initiatives. After the 2022 election, the “Tidö Agreement” (Moderaterna 2022), which formed the basis for the new right-wing government, designated endometriosis as a priority in efforts to increase funding for women’s health. In 2023, the Swedish Research Council (2023) and Forte (2023) mapped research in women’s health and diseases and found that more research is needed, specifically mentioning endometriosis, which led to concrete funding. An editorial in *The Lancet Obstetrics* (2025) notes that the past decade has seen “advances in diagnosis, therapeutic innovation, and growing public attention of endometriosis.”

Despite these positive developments, *Endometriosis UK* (2020) reports that most people in the UK (54%) still do not know what endometriosis is, with this

⁷² *Time Magazine* even proclaimed that 2014 may have been “the best year for women since the dawn of time” (Alter 2014), while *The Guardian* (2014) described the year as a “watershed.”

⁷³ The *Google Books Ngram Viewer* (2025) includes printed sources published between 1500 and 2022 in Google’s text corpora in English, Chinese (simplified), French, German, Hebrew, Italian, Russian, or Spanish.

⁷⁴ A *Google Trends* search in Sweden similarly shows October 2025 as the peak for the English term “endometriosis” (Google Trends 2025c) while the Swedish term “endometrios” peaked in 2015 (Google Trends 2025a).

figure rising to 74% among men. Similarly, a 2024 Swedish survey found that nearly half of the population had never heard of the condition, and the percentage increases to 80% among children and youth (EndoGyn 2024). This is concerning, given the normalization of menstrual pain and the risk that limited awareness may prevent people from seeking diagnosis and treatment. There is, therefore, still a significant need to increase public awareness of the condition. At the time of writing, 30 years have passed since the Fourth World Conference on Women adopted the Beijing Platform for Action, widely praised by feminists for its progressive global commitments. However, across Europe and the Americas, trends of de-democratization have emerged, accompanied by growing opposition to gender equality and threats to previous achievements in gender equality policy (UN Women 2025). Growing anti-gender movements also target sexual and reproductive rights (Kuhar and Paternotte 2017; Butler 2024). These trends could work against efforts to increase awareness of endometriosis, since efforts are often linked to advocacy for gender equality and reproductive rights. They could also pose additional challenges for transgender and gender-diverse individuals with endometriosis, who already face discrimination when seeking care and treatment (Jeffrey et al. 2024).

This study grew out of a sense of wonder about what it is like to live with endometriosis in a country like Sweden, often portrayed as a gender equality utopia. Not that it needs validation, but the findings of this study confirm that this utopia remains just that – a place that does not *yet* exist. Addressing the issues raised in this study is not only a matter of improving clinical practice but also of challenging the structures that determine whose pain is recognized as real and worthy of care. My hope, going forward, is that each person, whether doctor or friend, who encounters someone suffering from endometriosis will try to approach them with at least a little sense of wonder, marked by curiosity, fascination, and humility, and a willingness to learn, to understand, and to help relieve their pain. Perhaps such wonder could become a starting point for transforming not only individual encounters but also our institutions of care, respect, and esteem.

SAMMANFATTNING

Att erkänna endo: Om endometrios, genus och erkännande

Endometrios är en vanlig och smärtsam sjukdom som drabbar miljontals människor världen över – ungefär en av tio personer som menstruerar. Trots detta tar det ofta lång tid att få en diagnos, i genomsnitt fem till sju år i Sverige. Det är också vanligt att symptom som smärta förminskas, normaliseras eller ses som en naturlig del av att vara kvinna. På senare år har sjukdomen också blivit en viktig feministisk rättvisefråga. Men vilken roll spelar egentligen genus för hur det är att leva med endometrios? Hur är det att ha en sjukdom som inte alltid erkänns av andra? Hur påverkar det patienternas självrelation?

Denna avhandling presenterar en feministisk fenomenologisk analys av endometrios (endo) och erkännande. Det övergripande syftet är att fördjupa förståelsen av hur genusdynamiker och erkännande formar erfarenheter av denna ofta förbisedda sjukdom. Med genusdynamiker avses totaliteten av normer, relationer, interaktioner och subjektiviteter knutna till sociohistoriska föreställningar om kön, som tillsammans formar den levda verkligheten. Dessa dynamiker bör förstås som föränderliga, materiella och relationella, och de inbegriper flera olika maktförhållanden. Centralt för analysen är även G.W.F Hegels begrepp erkännande, främst uttolkat genom Axel Honneths erkännandefilosofi. Sedan mitten av 1990-talet har erkännande blivit centralt i diskussioner om social rättvisa, särskilt för att förstå drivkrafterna bakom sociala rörelser och för att förklara hur våra sociala relationer påverkar våra relationer till oss själva. Honneth förstår erkännande, i form av kärlek, respekt och social uppskattning, som avgörande för att utveckla en positiv personlig identitet eller självrelation. Det innebär att erkännande har både psykologiska och normativa dimensioner, då våra relationer med andra påverkar vår självrelation. Hegels filosofi har inspirerat viktiga tänkare för genusvetenskapen, som Simone de Beauvoir och Judith Butler, men här finns fortfarande mer att hämta när det gäller relationen mellan kön, erkännande och drivkrafterna bakom sociala rörelser.

Studien bygger på intervjuer med 15 personer i Sverige som fått diagnosen endometrios. Den närmar sig deras erfarenheter och krav på förändring som en samtida *kamp för erkännande*. Att samtala direkt med personer som påverkas av en

viss situation kan ge värdefulla empiriska insikter som bidrar till att förfina våra samhällsteorier. Genom att undersöka endometriosis ur ett erkännandeperspektiv, med utgångspunkt i den komplexa empiriska verkligheten och de icke-ideala villkor som endometriospatienter möter, syftar avhandlingen till att teoretisera rättvisa underifrån. I detta sammanhang kan fallet endometriosis ses både som ett nytt uttryck för och en fortsättning på tidigare feministiska och hälsorelaterade kamper för rättigheter, lika villkor och ökad kunskap – ofta med utgångspunkt i levd erfarenhet. Gemensamt för intervjupersonerna i denna studie är att samtliga tillhör den sista generationen av endometriospatienter i Sverige innan nationella riktlinjer för endometriosisvård infördes 2018. Det är viktigt att analysera dessa patientberättelser för att förstå de bakomliggande faktorerna som gjorde riktlinjerna nödvändiga och samtidigt bidra med fördjupad förståelse och kunskap som kan förbättra dagens situation.

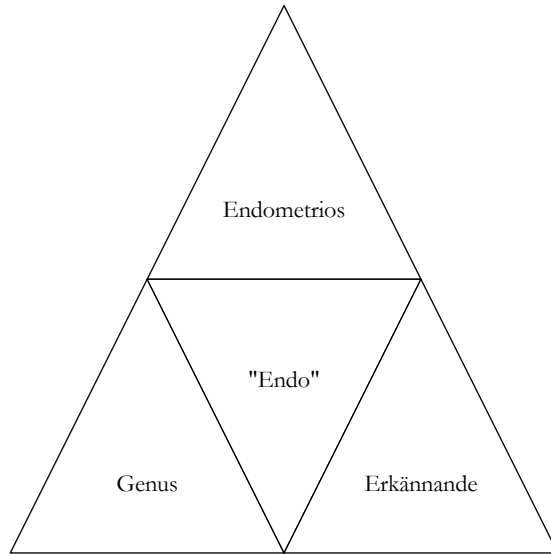
Mer specifikt undersöks fenomenet “endo” – såsom det framträder i intervjupersonernas livsvärld – genom att *identifiera*, *beskriva* och *analysera* generella aspekter och typiska drag i intervjupersonernas berättelser. Studien söker svar på följande frågeställning: Hur kan en empiriskt förankrad filosofisk undersökning av endometriosis klargöra samspelet mellan genus, erkännande och självrelation, och därigenom bidra till såväl empirisk kunskap som filosofisk teori? Denna fråga kan delas in i tre tematiska frågeställningar:

- I. Hur formar genusdynamiker och erkännandeprocesser i intervjupersonernas livsvärld deras erfarenheter av att leva med endometriosis (endo), och hur påverkar dessa erfarenheter deras självrelation och motivation att förändra sin personliga och kollektiva livssituation?
- II. Hur kan erfarenheterna tematiseras genom att identifiera generella aspekter och typiska drag i intervjuberättelserna?
- III. Hur kan empiriskt förankrade begrepp utvecklas utifrån dessa berättelser och därmed berika och nyansera teorier om endometriosis, genus och erkännande?

Genom att presentera en fenomenologi baserad på intervjupersonernas berättelser är målet både att söka empiriska svar på dessa frågor och att utveckla empiriskt förankrade begrepp som belyser aspekter av deras levda verklighet. Den eftersträlvade fördjupade förståelsen omfattar därmed såväl empiriska insikter som teoriutveckling. De teman som identifieras och de begrepp som utvecklas presenteras i separata artiklar, vilka också knyter an till relevanta filosofiska debatter.

Endo som fenomen

Metodologiskt kan studien beskrivas som en empiriskt förankrad fenomenologi som syftar till att fånga hur "endo" som fenomen framträder i intervjupersonernas livsvärld. Genusdynamiker, erkännandeprocesser och det medicinska objektet endometriosis förstås som delar av en helhet som tillsammans konstituerar endo och möjliggör vissa erfarenheter av endometriosis.



Figur 2 Endo som fenomen

Med utgångspunkt i endo som fenomen och intervjupersonernas berättelser identifieras generella aspekter och typiska drag som kännetecknar hur endo framträder i livsvärlden. Tre huvudsakliga teman urskiljs: temporalitet, epistemiska praktiker och levd politik. Dessa ligger till grund för de empiriskt förankrade begreppen *endo time*, *endo episteme* och *endo politics*, vilka presenteras i varsin artikel. Tillsammans visar dessa tre teman inte bara *att* erkännande spelar en avgörande roll, utan också *hur* det manifesteras i levd verklighet.

Endo Time

Den första artikeln, "Endo Time: Endometriosis and the Flow of Recognition," undersöker det intrikata samspelet mellan temporalitet, genus och erkännande i relation till erfarenheter av endometriosis. Analysen av intervjumaterialet visade att tid är ett framträdande tema i intervjupersonernas erfarenheter av endometriosis. Trots tidens centrala betydelse har tidigare forskning om erfarenheter av endometriosis inte fokuserat på temporalitet. Erfarenheter av endometriosis präglas av

den cykliska menstruationen och dess könade karaktär samt av samhällets erkännande och respons. Detta gör endometriosis till ett belysande exempel för att undersöka sambandet mellan genus, erkännande och levd tid. Artikeln undersöker sambandet med utgångspunkt i följande frågor: Hur ser endons temporalitet ut? Hur framträder erkännandet av endo som tidsligt – vilka är dess takter och rytmer? Hur kan tid förstås som en fråga om genus och rättvisa?

Artikeln beskriver hur erkännande av endometriosis manifesteras i livsvärlden som en specifik orkestrering av tid, benämnd *endo time*. För att tematisera erkännandets temporalitet hämtas inspiration från feministisk teori och fenomenologi, framför allt idén om levd tid, liksom begrepp som *crip time* och queer temporalitet. Med utgångspunkt i Edmund Husserls beskrivning av vårt inre tidsmedvetande argumenterar artikeln för att filosofi inriktad på blivande (*becoming*) inte behöver implicera den optimism som kritiker ibland hävdar. För Husserl bygger tidsmedvetandet på ett konstituerande flöde och han skiljer mellan subjektiv och objektiv tid. Utan denna åtskillnad skulle vi inte uppleva att tiden går långsamt eller stannar, samtidigt som vi vet att detta skiljer sig från objektiv klocktid. Husserl erbjuder verktyg för att förstå levd tid som ett blivande eller erkännandeflöde – en dynamisk process som skapar temporala mönster i livsvärlden och som formar både sociala relationer och människors självrelationer. Utifrån intervjumaterialet identifieras tre teman eller temporala mönster som kännetecknar *endo time*: väntetid (I), cyklisk och kronisk tid (II) samt sedimenterad tid (III).

Väntetid handlar om den långa väntan på diagnos och behandling – och den negativa inverkan detta har på intervjupersonernas framtidsutsikter. Flera av dem berättar att de sökte vård för sina besvär redan vid menstruationsdebuten (*menarche*), men fick återkommande höra att “mens gör ont” eller att “smärta är normalt”. I ett fall började symptomen i 12-årsåldern, men diagnosen fastställdes först 28 år senare. En annan intervjuperson beskriver att “allt flöt samman” när hon tillbringade en hel höst i sängen på grund av sina symptom. Hon förklarar att det var först efter att ha påbörjat sin behandling som hon ens kunde tänka tanken att återuppta sina studier och föreställa sig en framtid igen. Dessa beskrivningar kan ses som att leva i *väntans temporalitet* och liknar det *passiva nu* som Megan Burke finner i Simone de Beauvoirs *Det andra könet* eller det Iris Marion Young kallar en *hämmande intentionalitet*. I förlängningen innebär detta en *fångenskap i nuet* och en förlust av framtiden – samt av möjligheten att forma sitt eget liv och sträva efter personliga mål. Flera intervjupersoner berättar att de har deltagit i aktivism och protester mot den långa väntan på diagnos, till exempel i Endometriosisförningens demonstrationer under parollen “Åtta år är inte OK.” Sådana initiativ kan ses som en kamp för erkännande, där *endo time* och att leva i väntetid är centrala delar i kritiken.

Cyklisk och kronisk tid fokuserar på symptomens olika temporaliteter och omgivningens reaktioner på dessa. Analysen visar att så länge smärtan var kopplad till menscykeln och var cyklisk *normaliserades* den ofta av andra, vilket ledde till att intervjupersonerna såg sig själva som ”lata” eller ”svagare” än andra eftersom de inte kunde hantera symptomen lika bra som andra. Detta påverkade deras självrelation negativt och gjorde det särskilt viktigt att få en diagnos eftersom detta sågs som bekräftelse på att de inte var ”galna” eller inbillade sig. Kronisk smärta, å andra sidan, *stigmatiserades* ofta av omgivningen. Intervjupersonerna beskriver det som svårt eller till och med skrämmande att tala om kroniska symptom eftersom det lätt kan uppfattas som att man gnäller eller är krånglig. Eftersom kroniska symptom bryter mot sociala förväntningar kopplade till produktivitet och tid kan de medföra vad studien benämner som *temporalt stigma*. Detta skapar ett dilemma: medan cyklisk smärta ses som alltför normal för att uppfattas som patologisk, betraktas kronisk smärta som alltför abnormal för att vara begriplig och passa in i konventionella livsmanus.

Sedimenterad tid, slutligen, handlar om konsekvenserna av förfluten tid i relation till kroppens konkreta materialitet, med fokus på två aspekter. För det första beskriver intervjupersonerna att symptom som kraftiga blödningar kan göra det svårt att följa kulturella vanor eller rytmer. Det kan handla om att följa den ”normala” frekvensen för toalettbesök, eller om att kunna delta i riskabla situationer som att övernatta hos vänner. Rädslan för att orsaka fläckar innebär att de behöver hantera både tid och identitet, eftersom den som har fläckar riskerar att ses som smutsig, slarvig eller till och med fattig. För det andra kan den långa väntan på diagnos medföra att endometriosvävnaden växer och sprider sig till flera organ, vilket ökar risken för kronisk smärta och infertilitet. Flera intervju personer berättar att deras tillstånd förvärrades på grund av den fördröjda diagnosen, vilket fick dem att tappa förtroende för läkare och vårdsystemet. Denna förlust av förtroende belyser erkännanderelationens ömtåliga natur och visar hur upplevda orättvisor kan motivera kampen för förändring.

Sammanfattningsvis bidrar artikeln till forskningen genom att använda begreppet *endo time* för att förklara hur erkännande av endometriosis kan förstås i temporala termer och hur det skapar en specifik orkestrering av tid. Artikeln argumenterar för en fenomenologisk förståelse av levd tid och ifrågasätter uppfattningen att ”blivande” implicerar optimism. Detta är viktigt eftersom blivande också kan belysa de negativa effekterna av passivitet i relation till en progressiv sjukdom som endo. *Endo time* kan förstås som en sammanflätning av kroppsliga processer som menstruation och samhällligt erkännande. Denna levda tid bör inte ses som extern i förhållande till kroppen utan som något som flödar genom den och sedimenteras över tid. Begreppet *endo time* syftar till att fånga komplex-

iteten i levd tid – och hur olika tidsförståelser samexisterar och är länkade. Erfarenheterna som analyseras här handlar om klocktid, såsom åren av fördröjd diagnos. De berör också väntan, temporala normer och temporalt stigma. Men istället för att se dessa erfarenheter som separata händelser i objektiv tid söker analysen beskriva dem som levda, som sedimenterade och konstituerande av hur och vilka vi blir.

Endo Episteme

Den andra artikeln, “Endo Episteme: Epistemic Injustice and the Misrecognition of Endometriosis”, handlar om diagnosprocessen och hur intervjupersonerna går från de första upplevelserna av smärta till kunskap om att de har en viss diagnos. Analysen av intervjumaterialet visade att vägen till kunskap har stor betydelse för hur endo upplevs och erkänns. Trots att det är välkänt att diagnosprocessen ofta är svår och lång finns det begränsad forskning om relationen mellan kunskapsprocesser och endometriosis. Framför allt saknas studier om vardagslivets epistemiska praktiker, deras roll i diagnosprocessen samt hur dessa praktiker samspekar med erkännandeprocesser. Artikeln undersöker detta genom att analysera hur kunskap om endometriosis framträder och blir meningsfull i livsvärlden med utgångspunkt i följande frågor: Hur lär sig intervjupersonerna om endo? Hur vinnns, förhandlas eller förloras kunskap? Vilka konsekvenser får detta för intervjupersonernas självrelation?

Genom att använda ett teoretiskt ramverk som kombinerar Axel Honneths erkännandeteori med Miranda Frickers diskussion om epistemisk orättvisa, presenteras en fenomenologisk analys av de levda epistemiska praktikerna som intervjupersonerna möter under den diagnostiska resan. Dessa praktiker utgör tillsammans *endo episteme*. Analysen identifierar viktiga epistemiska praktiker i intervjupersonernas livsvärld och teoretiserar dem som former av erkännande. Den tar sin utgångspunkt i tre centrala epistemiska processer: att bli ett kunskapssubjekt (I), att bli patient (II) och att bli kunskap (III).

Analysen av *att bli ett kunskapssubjekt* visar att erkännande genom *epistemiskt stöd* är avgörande för denna process. Omsorg eller stöd av detta slag är vanligt i nära relationer som präglas av kärlek och vänskap och skapar förutsättningar för det som kan kallas epistemiskt självförtroende eller epistemisk agens. Två epistemiska praktiker är särskilt viktiga här. Den första är *att-jämföra-med* (*comparing-with*) och syftar på att intervjupersonerna pratar om och jämför sina erfarenheter med andra i sin närhet, vilket gör det lättare att förstå och tolka erfarenheterna. *Att-jämföra-med* hjälper dem att avgöra om deras smärta eller andra symptom bör

förstås som normala, som något alla har, eller som onormala och därmed patologiska. Den andra praktiken är *kommunikativ validering (expressive uptake)* som handlar om vikten av att familj och vänner lyssnar och ger emotionellt stöd när intervjupersonerna delar med sig av sina erfarenheter av olika symptom. Denna typ av validering hjälper dem att artikulera och förstå sina egna känslor. Att-jämföra-med och att erhålla kommunikativ validering är båda viktiga former av epistemiskt stöd som främjar epistemisk agens. De underlättar processen att bli ett kunskapssubjekt i relation till endometrios och gör det enklare att ta steget och söka vård.

Processen *att bli patient* visar att *epistemisk respekt* är avgörande för att anses berättigad till vård. Världshälsoorganisationen (WHO) definierar hälsa som en grundläggande mänsklig rättighet. Samtidigt tyder intervjupersonernas erfarenheter av att inte bli tagna på allvar inom vården på att genusbias kan stå i vägen för denna rättighet i praktiken. I detta sammanhang kan epistemisk respekt ses som ett uttryck för att man blir lyssnad på och behandlas som jämlik med andra i rättslig och moralisk mening. Två praktiker är särskilt viktiga när det gäller att bli endometriospatient. Den första, *smärtans pedagogik*, utmärker sig på ett negativt sätt och tar sig uttryck genom den vitt spridda föreställningen att menssmärta i grunden är normalt. Denna praktik är så frekvent i intervjuerna att den framträder som ett mantra som lär unga hur de bör reagera på smärtan: genom att stå ut och ignorera den. Den som inte lever upp till detta ideal riskerar en trovärdighetskris eller att stämpas som "hysterisk" eller "hypokondriker." Den andra praktiken är *kampen för diagnos* och syftar på de taktiker och strategier intervjupersonerna använder för att få en diagnos och därigenom uppnå status som legitim patient. Exempel på sådana strategier är att uppsöka flera olika läkare, ofta utifrån tips och rekommendationer från andra endometriospatienter, eller att ta med en man till läkarbesöket för att öka sina chanser att bli lyssnad på. Att få en diagnos och bli patient är viktigt för deras självrelation eftersom det bekräftar att de inte är "galna" eller att "allt sitter i huvudet."

Slutligen visar analysen att *epistemisk anseende* är avgörande för *att bli kunskap*. Epistemiskt anseende kan ses som ett uttryck för den status endometrios som har i samhällets gemensamma hermeneutiska resurser, det vill säga delade tolkningar, uttryck och ramar för kommunikation, självförståelse och kunskapsutbyte. Fricker menar att individer kan vara hermeneutiskt marginaliserade om det saknas begrepp, meningssammanhang och tolkningsramar för att förstå deras erfarenhet. Även om en viss typ av erfarenhet delas av en ingrupp kan den vara obegriplig för omgivningen eftersom gruppen inte har getts möjlighet att bidra till samhällets gemensamma kunskapsbas. Två epistemiska praktiker är särskilt viktiga här. Den första är *okunskapens epistemologi* och handlar om bristen på medicinsk kunskap om endometrios och andra kvinnodominerade sjukdomar.

Intervjupersonerna beskriver till exempel att sjukdomen har låg status och att deras symptom kan uppfattas som "konstiga," eller klassificeras med hjälp av "slaskdiagnoser." Den andra praktiken är *epistemisk aktivism* och handlar om intervjupersonernas politiska engagemang för ökad kunskap, bland annat genom att kräva nationella riktlinjer för vård vid endometrios, vilket slutligen infördes i Sverige 2018.

Genom att analysera och beskriva *endo episteme* fördjupas förståelsen av vardagslivets epistemiska praktiker under den diagnostiska resan mot kunskap om endometrios. Att belysa epistemiska hinder ur ett patientperspektiv bidrar till att förstå orsakerna till fördröjd diagnos och behandling, vilket är avgörande för att förbättra patienternas livskvalitet. Detta är särskilt viktigt eftersom sjukdom kan göra individer mer sårbara för epistemisk orättvisa. Artikeln visar att praktiker som *att-jämföra-med* och *kommunikativ validering* är centrala för att vinna kunskap. *Smärtans pedagogik* och *okunskapens epistemologi* illustrerar hur kunskap förloras snarare än vinnas. *Kampen för diagnos* och *epistemisk aktivism* exemplifierar hur kunskap förhandlas för att överkomma epistemiska hinder. Dessa praktiker kan ha en konkret inverkan på deras självrelation. I analysen finns exempel på att en brist på epistemiskt stöd sänker deras känsla av epistemiskt självförtroende och agens. Att inte erkännas som patient trots svåra symtom kopplas till en förlust av tilltro till både vården och sitt eget förnuft. Sammantaget visar dessa exempel att epistemisk orättvisa påverkar både kunskapen och kunskapssubjektet.

Endo Politics

Den tredje artikeln, "Endo Politics: How Identity Obstructs the Recognition of Endometriosis," handlar om intervjupersonernas strävan efter diagnos och behandling, vilket artikeln analyserar som en kamp för erkännande, benämnd *endo politics*. Analysen visade att kampen för diagnos och erkännande var ett viktigt tema i intervjumaterialet tillsammans med frågor rörande identitet. Det blev tydligt att hur intervjupersonerna kategoriserades i termer av kön, etnicitet och funktionalitet formade både deras erfarenheter och kampen för förändring. Medan tidigare forskning har undersökt vissa aspekter av endometrios och sociala rörelser, till exempel stödgrupper och onlineaktivism, har man inte tematiserat hur levda erfarenheter triggar sociala rörelser och vilken roll identitet spelar i kampen.

Artikeln bidrar genom att presentera en fenomenologisk analys av *endo politics*. För att klargöra förhållandet mellan erkännande och identitet används en debatt där Axel Honneth och Judith Butler diskuterar erkännande. I denna debatt föreslår Honneth en analytisk distinktion mellan två olika förståelser av erkännande: en kognitiv och en normativ. *Kognitivt* erkännande betonar begriplighet och social

kategorisering, medan *normativt* erkännande handlar om att tilldela någon en normativ status. Honneth menar att den senare är den grundläggande betydelsen som Hegel avsåg med begreppet. Butler föreslår en alternativ distinktion mellan erkännande och erkännbarhet (*recognizability*) där *erkännbarhet* syftar på de historiska ramarna för begriplighet som föregår och möjliggör *erkännande*. Med utgångspunkt i intervjumaterialet och denna debatt söker artikeln svar på följande frågor: Vad kännetecknar denna levda *endo politics*? Hur förhåller sig identitet till erkännande i detta fall? Endo är en könad sjukdom och en viktig feministisk fråga, men innebär det att identitet är "objektet" som intervjupersonerna söker erkännande för? För att besvara dessa frågor identifieras tre huvudsakliga teman som illustrerar hur *endo politics* framträder i intervjupersonernas livsvärld: att utveckla en kampanda (*fighting spirit*) (I), att bli ett "vi" (II) och att kämpa för inkludering (III).

Att utveckla en kampanda handlar om hur intervjupersonerna börjar tolka sina personliga erfarenheter som ett uttryck för orättvisa. I denna process är identitet inte det primära objektet för erkännande. Deras fokus är snarare på att tillgodose sina behov och att få sina symptom erkända i termer av diagnos och sjukdom. Men identitet beskrivs samtidigt som något som kommer i vägen för erkännande av deras behov. En intervjuperson beskriver det som att "ingen vill betala för kvinnosjukdomar". De beskriver också situationer där antingen deras kön eller ålder försvårar deras försök att få en diagnos genom att påverka deras trovärdighet och status – det påverkar deras *erkännbarhet* för att tala med Butler. I samband med känslan av orättvisa kopplad till deras identitet beskriver de också en personlig förändring där de går från att acceptera nederlag till att stå på sig, bli mer bestämda och kräva mer. Att utveckla en kampanda syftar just på denna förhöjda agens och beslutsamhet. Denna kampanda och känsla av orättvisa ackompanjeras ofta av en andra insikt: att det de själva varit med om drabbar många fler. Deras medvetenhet vidgas bortom det rent personliga och de börjar betrakta det personliga som politiskt och söker upp andra i samma situation. Att utveckla en kampanda kan därmed förstås som att bli del av det som forskning om sociala rörelser kallar protestpotentialen.

Att bli ett "vi" handlar i sin tur om formerandet av en kollektiv identitet tillsammans med andra endopatier. Några intervjupersoner berättar att de har gått med i Endometriosföreningen. Andra beskriver sitt deltagande i politisk aktivism, såsom demonstrationer för nationella riktlinjer för vård av endometriosis. Vissa nämner stödgrupper på sociala medier där de kan dela erfarenheter och hitta sammanhang tillsammans med andra. Flera av intervjupersonerna beskriver en stark känsla av "vi" i relation till endometriosiscommunityt. En av dem beskriver känslan: "Det är som att *vi* [...] endokrigare, endosystrar – vi är ju som ett systerskap, vi försöker ju... det är vi liksom, mot världen." Den känsla av "vi" kan

förstås i ljuset av Husserls beskrivningar av *Gemeingeist* och skapandet av en vi-intentionalitet. Erfarenheterna kan också förstås i ljuset av Iris Marion Youngs (2011, 44) beskrivning av gruppidentitet som en samhörighet baserad på "a certain social status, the common history that status produces, and self-identification." Att bli ett "vi" revolutionerar intervjupersonernas subjektivitet genom att skapa en kollektiv anda baserad på den upplevda orättvisa som deras position innebär. Men samtidigt som uttryck som "endosystrar" kan skapa enighet runt gemensamma mål kan de också fungera exkluderande.

Att kämpa för inkludering handlar om intervjupersonernas kamp för att utmana och expandera olika identitetskategorier som exkluderar dem. En intervjuperson beskriver till exempel vikten av att betona maktaspekter kopplade till hur kvinnosjukdomar försummas, samtidigt som man undviker ett exkluderande språk, till exempel genom att välja termer som "endosyskon" snarare än "endosystrar". Andra belyser hur osynliga sjukdomar som endometriosis ofta förbises i frågor om funktionsrätt, såsom rätten att använda tillgänglighetsanpassade säten i kollektivtrafiken. En intervjuperson med muslimsk bakgrund delar med sig av sina svårigheter med att diskutera endometriosis inom sin familj och sitt community och noterar att andra muslimska tjejer har börjat kontakta henne direkt med frågor om sjukdomen. Detta kan förstås som skapandet av ett alternativt "vi"-community och ligger i linje med den forskning som visat att aktivism är lättare att upprätthålla när en persons olika livssfärer står i samklang.

Sammantaget beskriver intervjupersonerna hur olika identitetskategorier, relaterade till kön, etnicitet eller funktionalitet, kan stå i vägen för erkännande och göra det svårare att anta sjukrollen. Skapandet av ett "vi" främjar kollektiv aktivism och skiftar kampen från det personliga till det politiska. Men så snart ett kollektivt "vi" har skapats, återkommer risken för exkludering och behovet av att revolutionera subjektiviteten. Kampen för inkludering komplicerar det nyligen etablerade "vi:et" liksom identiteters roll inom rörelsen. Det kan handla om språkanvändning, om att utmana befintliga kategorier eller om att skapa alternativa former av "vi." Artikeln bidrar till forskningen genom att tematisera hur personliga erfarenheter av endometriosis motiverar sociala rörelser och hur identitet spelar roll i kampen för förändring. För att nå en djupare förståelse av dessa erfarenheter argumenterar artikeln för att både Honneths och Butlers perspektiv på erkännande är användbara liksom deras syn på identitet, men att de inte bör blandas samman. Butlers perspektiv betonar social kategorisering, som främst handlar om gruppidentitet, medan Honneth fokuserar på personifierande erkännande genom kärlek, respekt och social uppskattning, vilket handlar om personlig identitet i bemärkelsen självrelation. Genom att kombinera aspekter av både Honneths och Butlers tänkande blir det möjligt att förstå att även om identitet inte utgör erkännandets objekt kan gruppidentiteter hindra personifierande

erkännandeakter. Intervjupersonerna upplever sådana hinder som bristande hänsyn till deras behov och rättigheter. Analysen visar därmed hur gruppidentiteter kan omfattas på olika sätt, men också ifrågasättas och omvandlas. Detta kan förstås som en pågående process eller dialektik mellan individ och kollektiv, personligt och politiskt, som aldrig definitivt tar slut.

Slutsatser

Det övergripande syftet med denna avhandling har varit att fördjupa förståelsen av hur genus och erkännande formar erfarenheter av endometriosis. Målet har varit att utforska erfarenheter på ett sätt som främjar både empirisk kunskap och filosofisk förståelse. Genom att analysera och teoretisera endometriosis som fenomenet "endo" har tre teman identifierats som karakteriserar dess manifestation i intervjupersonernas livsvärld. Dessa teman ligger till grund för de empiriskt förankrade begreppen *endo time*, *endo episteme* och *endo politics*.

Studien lyfter därmed fram tre centrala teman som förtjänar mer uppmärksamhet inom endometriosisforskning och policy. Eftersom den bygger på 15 djupintervjuer är resultaten inte avsedda att vara brett generaliserbara. Målet har varit att ge en rikare och djupare förståelse av detta specifika fenomen. Även om analysen därmed inte kan säga hur ofta dessa erfarenheter förekommer i en större population, kan insikterna utgöra en grund för vidare forskning, inklusive kvantitativa studier. Framför allt kan de vara till nytta för alla som lever med endometriosis och för de som möter drabbade individer eller är involverade i relevant beslutsfattande. Utöver patienter, familj och vänner inkluderar detta lärare, skolsköterskor, vårdpersonal, myndigheter och politiker.

För att ge några exempel: Analysen av *endo time* belyser inte bara den långa väntan på diagnos utan också denna väntans sociala, subjektiva och existentiella dimensioner. Att leva i *väntetid* handlar om mer än bara den faktiska väntetiden; det har också en emotionell påverkan. Intervjupersonerna berättar om känslor av övergivenhet och en negativ påverkan på sina framtidsutsikter. Detta ger en djupare förståelse och tillför ett existentiellt perspektiv på vikten av diagnos inom rimlig tid. Analysen av *endo episteme* visar att epistemiska praktiker är centrala för att förkorta tiden till diagnos och behandling. Det är viktigt att personer med endometriosis möter *epistemiskt stöd* och *kommunikativ validering* när de berättar om sina erfarenheter för familj eller vänner, eftersom detta påverkar deras självförtroende och motivation att söka vård. Utan sådant stöd blir det ännu viktigare att skolor och sjukvården erbjuder epistemiskt stöd och respekt utöver ren information. Intervjuerna visar att processen att söka vård innebär en onödigt tuff *kamp för diagnos*, där intervjupersonerna använder olika strategier för att bli tagna på allvar. Vi behöver därför gemensamt vänja oss av med *smärtans pedagogik*, vilket

innebär att sprida kunskap till unga för att förhindra att framtida generationer fortsätter att normalisera menssmärta.

När det gäller *endo politics* visar analysen att personliga erfarenheter av svårigheter att få diagnos och behandling leder till en kamp för erkännande och motiverar politisk mobilisering. Detta är ett tema som hittills har varit underutforskat i litteraturen. Även här berörs existentiella frågor, och temat illustrerar hur intervjupersonerna uppfattar bristen på medicinskt erkännande och vård som en könsbaserad orättvisa. Denna insikt tar sig uttryck i *att utveckla en kampanj*, en vilja att samlas med andra och *att bli ett "vi."* Här finns likheter med aktivism inom både feministiska och hälsobaserade sociala rörelser, som till exempel bröstcancerörelsen. Intervjupersonernas berättelser visar också att identitetskategorier ibland kan utgöra ett hinder för erkännande. Det kan handla om att endometrios i sig betraktas som en kvinnosjukdom, vilket ger lägre status, eller att leva med endometrios och vara icke-binär, tillhöra en etnisk minoritet eller ha tillgänglighetsbehov som förbises på grund av sjukdomens osynlighet. Sådana erfarenheter motiverar dem *att kämpa för inkludering*.

Utöver dessa konkreta teman presenterar studien en feministisk fenomenologi av ett underutforskat fenomen och bidrar därmed till tidigare feministiska fenomenologiska studier som har utforskat teman såsom menstruation, graviditet, födande, bröst, åldrande, sjukdom och smärta. Den tillför också sjukdomsberättelser av ett könat tillstånd som har flera likheter med andra sjukdomar som främst drabbar kvinnor. En studie från 2021 visade att USA:s nationella hälsoinstitut, världens största finansär av biomedicinsk forskning, tilldelar en oproportionerligt större andel av sina resurser till sjukdomar som främst drabbar män, på bekostnad av de som huvudsakligen påverkar kvinnor. Endometrios nämns uttryckligen som en av de mest underfinansierade kvinnodominerade sjukdomarna. Därmed förblir endometrios ett paradigmiskt fall som befinner sig i skärningspunkten mellan kön, hälsa och rättvisa, nära kopplat till feministiska frågor om stigmatisering och skam kring menstruation, jämställdhet och hälsa samt hysterisering av kvinnliga patienter.

Genom att undersöka *endo* ur ett erkännandeperspektiv illustrerar denna avhandling hur Hegels erkännandebegrepp kan berika genusstudier och feministisk fenomenologi, utöver bidragen från Beauvoir och Butler. Honneths erkännandeteori, som beskriver olika former av erkännande, är särskilt användbar för att analysera fenomen som *endo*, då den knyter samman individens självrelation och sociala relationer med de dynamiker som driver social förändring. Genom att kombinera erkännandeteori och fenomenologi i en analys av genusdynamiker utvecklas här en *feministisk erkännandefenomenologi*. Detta ramverk har potential att användas i analysen av andra fenomen, kanske framför allt när det handlar om att teoretisera rättvisefrågor med utgångspunkt i människors levda verklighet. På

samma vis kan de empiriskt förankrade begreppen utgöra en modell för andra feministiska och genusvetenskapliga analyser. De kan visa sig användbara för att studera hur andra genus- och rättvisefrågor förhåller sig till tid, epistemiska praktiker och levd politik bortom erfarenheter av sjukdom.

Studien verkar också i den kritiska teorins anda genom att teoretisera rättvisa och erkännande underifrån, med utgångspunkt i empiri och de icke-ideala villkor som intervjupersonerna möter. Analysen av hur genusdynamiker samverkar med olika former av erkännande utgör också ett bidrag till erkännandeteori. Studien visar hur olika aspekter av erkännande kan tematiseras separat genom att fokusera på tid, epistemiska praktiker och levd politik. Detta är ett första steg i att undersöka hur forskning om genusdynamik kan berika erkännandeteori, men det pekar på en stor potential för att fortsätta utveckla ett ramverk för en feministisk erkännandefenomenologi. En slutsats är att metodiken som använts i denna studie fördjupar vår förståelse av både förtryckets strukturer *och* de resurser som krävs för att konkret övervinna det i det konkreta fallet endometriosis. Som Miranda Fricker med rätta påpekar är en av erkännandeteorins främsta styrkor att den erbjuder något positivt. Den belyser de sociala relationer och institutioner som behövs för att främja positiva relationer till oss själva och andra. Genom att analysera erfarenheter av orättvisa och miserkännande kan vi nå insikter om deras positiva motsvarigheter och hitta sätt att förverkliga dem. Förhoppningsvis kan *Recognizing Endo* därmed utgöra ett bidrag i relation till en av vår tids viktiga feministiska kamper.

REFERENCES

- Abend, Gabriel. 2008. "The Meaning of "Theory."” *Sociological Theory* 26 (2): 173–99.
- Ahmed, Sara. 2006. *Queer Phenomenology: Orientations, Objects, Others*. Duke University Press.
- Åkerman, Eva, Anna Wångborg, Maria Persson, Renita Sörensdotter, and Marie Klingberg-Allvin. 2024. "Navigating Menstrual Stigma and Norms: A Qualitative Study on Young People’s Menstrual Experiences and Strategies for Improving Menstrual Health.” *BMC Public Health* 24 (1): 3401.
- Alcoff, Linda Martín. 2006. *Visible Identities: Race, Gender and the Self*. Oxford University Press.
- Alcoff, Linda Martín. 2007. "Fraser on Redistribution, Recognition, and Identity.” *European Journal of Political Theory* 6 (3): 255–65.
- Allaire, Catherine, Tuba Aksoy, Mohamed Bedaiwy, et al. 2017. "An Interdisciplinary Approach to Endometriosis-Associated Persistent Pelvic Pain.” *Journal of Endometriosis and Pelvic Pain Disorders* 9 (2): 77–86.
- Allen, Amy. 2016. *The End of Progress: Decolonizing the Normative Foundations of Critical Theory*. Columbia University Press.
- Allen, Amy. 2021. "Recognizing Ambivalence: Honneth, Butler, and Philosophical Anthropology.” In *Recognition and Ambivalence*, edited by Heikki Ikäheimo, Kristina Lepold, and Titus Stahl. Columbia University Press.
- Al-Saji, Alia. 2010. "Bodies and Sensings: On the Uses of Husserlian Phenomenology for Feminist Theory.” *Continental Philosophy Review* 43 (1): 13–37.
- Al-Saji, Alia. 2017. "Feminist Phenomenology.” In *The Routledge Companion to Feminist Philosophy*, edited by Ann Garry, Serene J. Khader, and Alison Stone. Taylor & Francis Group.
- Alson, Sara. 2024. *Endometriosis and Adenomyosis Diagnosed by Ultrasonography. Aspects Related to Fertility Treatment Outcomes [Doctoral Dissertation Lund University]*. Lund University.
- Alter, Charlotte. 2014. "This May Have Been the Best Year for Women Since the Dawn of Time.” *TIME*, December 23. <https://time.com/3639944/feminism-2014-womens-rights-ray-rice-bill-cosby/>.
- Altman, Meryl. 2007. "Beauvoir, Hegel, War.” *Hypatia* 22 (3): 66–91.
- Aristotle. 2009. *The Nicomachean Ethics*. Oxford World’s Classics. Oxford University Press.
- Aspers, Patrik, and Ugo Corte. 2019. "What Is Qualitative in Qualitative Research.” *Qualitative Sociology* 42 (2): 139–60.
- As-Sanie, Sawsan, Rebecca Black, Linda C. Giudice, et al. 2019. "Assessing Research Gaps and Unmet Needs in Endometriosis.” *American Journal of Obstetrics and Gynecology* 221 (2): 86–94.
- Ballard, Karen, Karen Lowton, and Jeremy Wright. 2006. "What’s the Delay? A Qualitative Study of Women’s Experiences of Reaching a Diagnosis of Endometriosis.” *Fertility and Sterility* 86 (5): 1296–301.
- Ballweg, Mary Lou. 1997. "Blaming the Victim. The Psychologizing of Endometriosis.” *Obstetrics and Gynecology Clinics of North America* 24 (2): 441–53.

- Ballweg, Mary Lou. 2010. "News from the Endometriosis Movement." *Journal of Endometriosis* 2 (3): 164–67.
- Batt, Ronald E. 2011. *A History of Endometriosis*. Springer London.
- Bauer, Nancy. 2011. Review of *The Second Sex*, by Simone de Beauvoir. *Notre Dame Philosophical Reviews*.
- Beauvoir, Simone de. (1949) 1956. *The Second Sex*. Translated by H. M. Parshley. Jonathan Cape.
- Beauvoir, Simone de. 1976. *The Ethics Of Ambiguity*. Later Printing edition. Citadel/Kensington Books.
- Beauvoir, Simone de. (1949) 2011. *The Second Sex*. Translated by Constance Borde and Sheila Malovany-Chevallier. Vintage Classics.
- Benhabib, Seyla. 1992. "On Hegel, Women and Irony." In *Situating the Self*. Routledge.
- Benney, M., and E. C. Hughes. 1970. "Of Sociology and the Interview." In *Sociological Methods: A Source Book*, by N. K. Denzin. Butterworth.
- Bertaux, Daniel. 1981. "From the Life-History Approach to the Transformation of Sociological Practice." In *Biography and Society: The Life History Approach in the Social Sciences*. SAGE Studies in International Sociology. Sage.
- Björk, Emma. 2024. *Immunosuppressive Mechanisms in Endometriosis: A Focus on the Role of Exosomes [Doctoral Dissertation Umeå University]*. Umeå University.
- Bonetto, Sandra. 2006. "Race and Racism in Hegel." *Minerva: An Internet Journal of Philosophy* 10 (1). <https://minerva.mic.ul.ie/vol10/Hegel.html>.
- Bordo, Susan. 1993. "Feminism, Foucault and the Politics of the Body." In *Up Against Foucault*, edited by Caroline Ramazanoglu. Routledge.
- Bordo, Susan. 2004. *Unbearable Weight: Feminism, Western Culture, and the Body*. University of California Press.
- Boström, P., L. Lövkvist, M. Gustafsson, et al. 2012. "Cost of Illness in Women with Endometriosis." Pt. PIH14. Sec. A538. *Value in Health* 15 (7).
- Braun, Virginia, and Victoria Clarke. 2022. *Thematic Analysis: A Practical Guide*. SAGE Publications.
- Brecht, Bertolt, and Eric Bentley. 1961. "On Chinese Acting." *The Tulane Drama Review* 6 (1): 130–36.
- Brinkmann, Svend, and Steinar Kvale. 2015. *InterViews: Learning the Craft of Qualitative Research Interviewing*. Sage Publications.
- Brown, Phil, Stephen Zavestoski, Sabrina McCormick, Brian Mayer, Rachel Morello-Frosch, and Rebecca Gasior Altman. 2004. "Embodied Health Movements: New Approaches to Social Movements in Health." *Sociology of Health & Illness* 26 (1): 50–80.
- Burke, Megan M. 2018. "Gender as Lived Time: Reading the Second Sex for a Feminist Phenomenology of Temporality." *Hypatia* 33 (1): 111–27.
- Butler, Judith. 1986. "Sex and Gender in Simone de Beauvoir's Second Sex." *Yale French Studies*, no. 72: 35–49.
- Butler, Judith. 1987. *Subjects of Desire: Hegelian Reflections in Twentieth-Century France*. Columbia University Press.
- Butler, Judith. 1988. "Performative Acts and Gender Constitution: An Essay in Phenomenology and Feminist Theory." *Theatre Journal* 40 (4): 519–31.
- Butler, Judith. 1990. *Gender Trouble: Feminism and the Subversion of Identity*. Routledge.
- Butler, Judith. 1993. *Bodies That Matter. On the Discursive Limits of "Sex."* Routledge.
- Butler, Judith. 1997. "Merely Cultural." *Social Text*, no. 52/53: 265–77.
- Butler, Judith. 2000. *Antigone's Claim*. Columbia University Press.
- Butler, Judith. 2004a. *Precarious Life: The Powers of Mourning and Violence*. Verso.

- Butler, Judith. 2004b. *Undoing Gender*. Routledge.
- Butler, Judith. 2008. "Taking Another's View: Ambivalent Implications." In *Reification: A New Look At An Old Idea*, edited by Axel Honneth. Oxford University Press.
- Butler, Judith. 2009. *Frames of War: When Is Life Grievable?* Verso.
- Butler, Judith. 2019. "Genius or Suicide." *Politics & Economics*. *London Review of Books*, October 24. <https://www.lrb.co.uk/the-paper/v41/n20/judith-butler/genius-or-suicide>.
- Butler, Judith. 2021a. "Recognition and Mediation: A Second Reply to Axel Honneth." In *Recognition and Ambivalence*, edited by Heikki Ikäheimo, Kristina Lepold, and Titus Stahl. Columbia University Press.
- Butler, Judith. 2021b. "Recognition and the Social Bond: A Response to Axel Honneth." In *Recognition and Ambivalence*, edited by Heikki Ikäheimo, Kristina Lepold, and Titus Stahl. Columbia University Press.
- Butler, Judith. 2024. *Who's Afraid of Gender?* Penguin Books.
- Cairns, Dorion. 2013. "An Approach to Phenomenology." In *Philosophical Essays in Memory of Edmund Husserl*, edited by Marvin Farber. Harvard University Press.
- Carel, Havi. 2016. *Phenomenology of Illness*. First edition. Oxford University Press.
- Carleheden, Mikael. 2021. "How to Criticize? On Honneth's Method." *Distinktion: Journal of Social Theory* 22 (3): 299–318.
- Cavarero, Adriana. 1995. *In Spite of Plato: A Feminist Rewriting of Ancient Philosophy*. Polity Press.
- Chmielewski, Terrence L. 2017. "Empathic Listening." In *The SAGE Encyclopedia of Communication Research Methods*. SAGE Publications, Inc.
- Clark, Michelle. 2012. *Experiences of Women With Endometriosis: An Interpretative Phenomenological Analysis [Doctoral Dissertation Queen Margaret University]*.
- Collins, Patricia Hill. 1990. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. Unwin Hyman.
- Collins, Patricia Hill. 1998. "It's All in the Family: Intersections of Gender, Race, and Nation." *Hypatia* 13 (3): 62–82.
- Connolly, Julie. 2010. "Love in the Private: Axel Honneth, Feminism and the Politics of Recognition." *Contemporary Political Theory* 9 (4): 414–33.
- Cox, Helen, Lorraine Henderson, Natalie Andersen, Glenda Cagliarini, and Chantal Ski. 2003. "Focus Group Study of Endometriosis: Struggle, Loss and the Medical Merry-Go-Round." *International Journal of Nursing Practice* 9 (1): 2–9.
- Cox, Helen, Lorraine Henderson, Ros Wood, and Glenda Cagliarini. 2003. "Learning to Take Charge: Women's Experiences of Living with Endometriosis." *Complementary Therapies in Nursing and Midwifery* 9 (2): 62–68.
- CSDH. 2008. *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health*. Commission on Social Determinants of Health. World Health Organization. <https://www.who.int/publications/i/item/WHO-IER-CSDH-08.1>.
- Culley, L., C. Law, N. Hudson, et al. 2013. "The Social and Psychological Impact of Endometriosis on Women's Lives: A Critical Narrative Review." *Human Reproduction Update* 19 (6): 625–39.
- Culley, L., C. Law, N. Hudson, H. Mitchell, E. Denny, and N. Raine-Fenning. 2017. "A Qualitative Study of the Impact of Endometriosis on Male Partners." *Human Reproduction* 32 (8): 1667–73.
- Davis, Kathy. 2014. "Intersectionality as Critical Methodology." In *Writing Academic Texts Differently: Intersectional Feminist Methodologies and the Playful Art of Writing*, edited by Nina Lykke. Routledge.

- De Boer, Marjolein, and Kristin Zeiler. 2024. "Qualitative Critical Phenomenology." *Phenomenology and the Cognitive Sciences*, ahead of print. <https://doi.org/10.1007/s11097-024-10034-7>.
- De Boer, Marjolein, Kristin Zeiler, and Jenny Slatman. 2019. "Sharing Lives, Sharing Bodies: Partners Negotiating Breast Cancer Experiences." *Medicine, Health Care and Philosophy* 22 (2): 253–65.
- De Nardi, P., and S. Ferrari. 2011. "Diagnosis." In *Deep Pelvic Endometriosis: A Multidisciplinary Approach*, edited by Paola De Nardi and Stefano Ferrari. Springer Milan.
- Della Corte, Luigi, Claudia Di Filippo, Olimpia Gabrielli, et al. 2020. "The Burden of Endometriosis on Women's Lifespan: A Narrative Overview on Quality of Life and Psychosocial Wellbeing." *International Journal of Environmental Research and Public Health* 17 (13): 4683.
- Denny, Elaine. 2004. "Women's Experience of Endometriosis." *Journal of Advanced Nursing* 46 (6): 641–48.
- Denny, Elaine. 2009. "I Never Know from One Day to Another How I Will Feel: Pain and Uncertainty in Women with Endometriosis." *Qualitative Health Research* 19 (7): 985–95.
- Denny, Elaine, and K. S. Khan. 2006. "Systematic Reviews of Qualitative Evidence: What Are the Experiences of Women with Endometriosis?" *Journal of Obstetrics and Gynaecology* 26 (6): 501–6.
- Dolezal, Luna. 2015a. *The Body and Shame: Phenomenology, Feminism, and the Socially Shaped Body*. Lexington Books.
- Dolezal, Luna. 2015b. "The Phenomenology of Shame in the Clinical Encounter." *Medicine, Health Care and Philosophy* 18 (4): 567–76.
- Dryden, Jane. 2013. "Hegel, Feminist Philosophy, and Disability: Rereading Our History." *Disability Studies Quarterly* 33 (4): 1–1.
- Ellis, Carolyn. 2007. "Telling Secrets, Revealing Lives: Relational Ethics in Research With Intimate Others." *Qualitative Inquiry* 13 (2): 3–29.
- EndoGyn. 2024. "Nästan hälften av Sveriges befolkning har inte hört talas om Endometriosis." Endogyn.se. <https://www.endogyn.se/nyheter/nastan-halfven-av-sveriges-befolkning-har-inte-hort-talas-om-endometriosis>.
- Endometriosis Association. 2025. "Endometriosis Awareness Month | March 2020." *Endometriosis Association*. <https://endometriosisassn.org/endometriosis-awareness-month-2021/>.
- Endometriosis UK. 2020. "Endometriosis Awareness Month 2020 Launches to Tackle the Fact 54% Don't Know about Endometriosis | Endometriosis UK." <https://www.endometriosis-uk.org/endometriosis-awareness-month-2020-launches-tackle-fact-54-dont-know-about-endometriosis>.
- European Institute for Gender Equality. 2024. "Sweden | 2024 | Gender Equality Index." <https://eige.europa.eu/gender-equality-index/2023/country/SE>.
- Fichte, Johann Gottlieb. (1796) 2000. *Foundations of Natural Right: According to the Principles of the Wissenschaftslehre*. Edited by Frederick Neuhouser. Translated by Michael Baur. Cambridge University Press.
- Finch, Janet. 1984. "It's Great to Have Someone to Talk to: The Ethics and Politics of Interviewing Women." In *Social Researching*. Routledge.
- Fink, Eugen. 1981. "Operative Concepts in Husserl's Phenomenology." In *Apriori and World: European Contributions to Husserlian Phenomenology*, edited by William McKenna, Robert M. Harlan, and Laurence E. Winters. Springer Netherlands.

- Fisher, Linda. 2014. "The Illness Experience: A Feminist Phenomenological Perspective." In *Feminist Phenomenology and Medicine*, edited by Lisa Folkmarson Käll and Kristin Zeiler. State University of New York Press.
- Forte. 2023. *Kvinnors hälsa och sjukdomar – kartläggning och analys av forskningsbehov*. Forte – Forskningsrådet för hälsa, arbetsliv och välfärd. <https://forte.se/upptack-forskning/publikationer/kvinnors-halsa-och-sjukdomar---kartlaggning-och-analys-av-forskningsbehov>.
- Foucault, Michel. 1971. "Orders of Discourse." *Social Science Information* 10 (2): 7–30.
- Foucault, Michel. 1980. *Power/Knowledge: Selected Interviews and Other Writings 1972-1977*. Pantheon.
- Fraser, Nancy. 1985. "What's Critical about Critical Theory? The Case of Habermas and Gender." *New German Critique*, no. 35: 97–131.
- Fraser, Nancy. 2000. "Rethinking Recognition." *NEW LEFT REVIEW*, no. 3: 107–20.
- Fraser, Nancy, and Axel Honneth. 2003. *Redistribution or Recognition?: A Political-Philosophical Exchange*. Verso.
- Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford University Press.
- Fricker, Miranda. 2015. "Epistemic Contribution as a Central Human Capability." In *The Equal Society: Essays on Equality in Theory and Practice*, edited by George Hull. Lexington Books.
- Fricker, Miranda. 2018. "Epistemic Injustice and Recognition Theory: A New Conversation - Afterword." *Feminist Philosophy Quarterly* 4 (4).
- Frid, Johanna. 2018. *Nora eller Brinn Oslo brinn*. Ellerströms.
- Gallagher, Shaun. 2012. "Taking Stock of Phenomenology Futures." *Southern Journal of Philosophy* 50 (2): 304–18.
- Gallagher, Shaun, and Dan Zahavi. 2007. *The Phenomenological Mind: An Introduction to Philosophy of Mind and Cognitive Science*. Taylor & Francis.
- Ganesh, Ahalya, Maria Temmes, and Lilli Aini Rokkonen. 2025. "Gendering Chronic Illness in Patient Advocacy." *Australian Feminist Studies* 40 (124–125): 261–76.
- Garcia, Manon. 2025. "Unveiling Existential Ambiguity: The Role of Recognition in Simone de Beauvoir's Philosophy." In *Recognition: Historical and Philosophical Perspectives*. Routledge.
- Giacomozzi, Maddalena, Jip Bouwens, Stéphane Guy Aubin, Hester Pastoor, Petra Verdonk, and Annemiek Nap. 2024. "Transgender and Gender Diverse Individuals Embodying Endometriosis: A Systematic Review." *Frontiers in Medicine* 11 (November): 1430154.
- Giacomozzi, Maddalena, Donna Ruumpul, Robert de Leeuw, et al. 2026. "Endometriosis Among Transgender and Gender Diverse Patients Imaging Study (ETRIS)." *Journal of Minimally Invasive Gynecology* 33 (3): 308–15.
- Gibson-Helm, Melanie, Helena Teede, Andrea Dunaif, and Anuja Dokras. 2016. "Delayed Diagnosis and a Lack of Information Associated With Dissatisfaction in Women With Polycystic Ovary Syndrome." *The Journal of Clinical Endocrinology and Metabolism* 102 (2): 604–12.
- Giorgi, Amedeo. 2009. *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach*. Duquesne University Press.
- Giorgi, Amedeo. 2011. "IPA and Science: A Response to Jonathan Smith." Sec. 2. *Journal of Phenomenological Psychology*, no. 42 (January): 195–216.
- Giudice, Linda C., and Lee C. Kao. 2004. "Endometriosis." *The Lancet* 364 (9447): 1789–99.

- Glaser, Barney G., and Anselm L. Strauss. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine Publishing Company.
- Goode, W. J., and P. K. Hatt. 1952. *Methods in Social Research*. McGraw Hill.
- Google Books Ngram Viewer. 2025. "Endometriosis." Google Books Ngram Viewer. https://books.google.com/ngrams/graph?content=endometriosis&year_start=1900&year_end=2022&corpus=en&smoothing=3.
- Google Trends. 2025a. "Endometriosis [in Sweden]." Google Trends. <https://trends.google.com/trends/explore?date=all&geo=SE&q=endometriosis&hl=sv>.
- Google Trends. 2025b. "Endometriosis." Google Trends. <https://trends.google.com/trends/explore?date=all&q=endometriosis&hl=sv>.
- Google Trends. 2025c. "Endometriosis [in Sweden]." Google Trends. <https://trends.google.com/trends/explore?date=all&geo=SE&q=endometriosis&hl=sv>.
- Gregoratto, Federica. 2015. "Pathology of Love as Gender Domination: Recognition and Gender Identities in Axel Honneth and Jessica Benjamin." *Studies in Social and Political Thought* 25 (December): 82–98.
- Grosz, Elizabeth. 1994. *Volatile Bodies: Toward a Corporeal Feminism*. Indiana University Press.
- Grundström, Hanna. 2018. *Disclosing the Invisible: Experiences, Outcomes and Quality of Endometriosis Healthcare [Doctoral Dissertation Linköping University]*. Linköping University.
- Grundström, Hanna, Siw Alehagen, Preben Kjølhed, and Carina Berterö. 2018. "The Double-Edged Experience of Healthcare Encounters among Women with Endometriosis: A Qualitative Study." *Journal of Clinical Nursing* 2018 (27): 205–11.
- Guenther, Lisa. 2013. *Solitary Confinement: Social Death and Its Afterlives*. University of Minnesota Press.
- Guenther, Lisa. 2021. "Six Senses of Critique for Critical Phenomenology." *Puncta: Journal of Critical Phenomenology* 4 (2): 5–23.
- Guest, Greg, Arwen Bunce, and Laura Johnson. 2006. "How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability." *FIELD METHODS*, no. 1: 59.
- Hallström, Ina. 2024a. "Endo Episteme: Epistemic Injustice and the Misrecognition of Endometriosis." *Feminist Philosophy Quarterly* 10 (4).
- Hallström, Ina. 2024b. "Endo Time: Endometriosis and the Flow of Recognition." *Hypatia* 39 (2): 423–43.
- Hallström, Ina. 2026. *Endo Politics: How Identity Obstructs the Recognition of Endometriosis [Manuscript Submitted for Publication]*.
- Haraway, Donna. 1988. "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." *Feminist Studies* 14 (3): 575–99.
- Harding, Sandra. 1986. *The Science Question in Feminism*. Cornell University Press.
- Harris, Kimberly Ann, and Daniel James. 2026. "Debating Hegel's Racism." *Philosophy Compass* 21 (1): e70072.
- Hegel, Georg Wilhelm Friedrich. (1807) 1977. *Phenomenology of Spirit*. Oxford University Press.
- Hegel, Georg Wilhelm Friedrich. (1821) 1991. *Elements of the Philosophy of Right*. Edited by Allen W. Wood. Translated by Hugh Barr Nisbet. Cambridge University Press.
- Heidegger, Martin. (1954) 1977. *The Question Concerning Technology, and Other Essays*. Harper & Row.
- Heidegger, Martin. (1927) 2010. *Being and Time*. Translated by Joan Stambaugh. State University of New York Press.

- Heinämaa, Sara. 2003. *Toward a Phenomenology of Sexual Difference: Husserl, Merleau-Ponty, Beauvoir*. Rowman & Littlefield Publishers.
- Heinämaa, Sara. 2014. “‘An Equivocal Couple Overwhelmed by Life’: A Phenomenological Analysis of Pregnancy.” *philoSOPHIA* 4 (1): 31–49.
- Hemmings, Clare. 2011. *Why Stories Matter: The Political Grammar of Feminist Theory*. Duke University Press.
- Høffding, Simon. 2019. “Chapter 2: How Should We Study Musical Absorption? The Phenomenological Interview.” In *A Phenomenology of Musical Absorption*. Palgrave Macmillan.
- Høffding, Simon, and Kristian Martiny. 2016. “Framing a Phenomenological Interview: What, Why and How.” *Phenomenology and the Cognitive Sciences* 15 (4): 539–64.
- Honneth, Axel. 1993. *The Critique of Power: Reflective Stages in a Critical Social Theory*. MIT Press.
- Honneth, Axel. 1995. *The Struggle for Recognition: The Moral Grammar of Social Conflicts*. Translated by Joel Anderson. Polity Press.
- Honneth, Axel. 2002. “Grounding Recognition: A Rejoinder to Critical Questions.” *Inquiry* 45 (4): 499–519.
- Honneth, Axel. 2003a. “Redistribution as Recognition: A Response to Nancy Fraser.” In *Redistribution or Recognition?: A Political-Philosophical Exchange*, by Axel Honneth and Nancy Fraser. Verso.
- Honneth, Axel. 2003b. “The Point of Recognition: A Rejoinder to the Rejoinder.” In *Redistribution or Recognition?: A Political-Philosophical Exchange*, by Nancy Fraser and Axel Honneth. Verso.
- Honneth, Axel. 2004. “Recognition and justice: Outline of a plural theory of justice.” *Acta Sociologica* 47 (4): 351–64.
- Honneth, Axel. 2008a. “Critical Theory.” In *The Routledge Companion to Twentieth Century Philosophy*, edited by Dermot Moran. Routledge.
- Honneth, Axel. 2008b. *Reification: A New Look at an Old Idea*. Oxford University Press.
- Honneth, Axel. 2008c. “Reification and Recognition: A New Look at an Old Idea.” In *Reification: A New Look At An Old Idea*, by Axel Honneth. Oxford University Press.
- Honneth, Axel. 2008d. “Rejoinder.” In *Reification: A New Look At An Old Idea*, by Axel Honneth. Oxford University Press.
- Honneth, Axel. 2014a. *Disrespect: The Normative Foundations of Critical Theory*. Polity Press.
- Honneth, Axel. 2014b. “Facets of the Presocial Self: Rejoinder to Joel Whitebook.” In *The I in We*. Polity Press.
- Honneth, Axel. 2014c. *Freedom’s Right: The Social Foundations of Democratic Life*. Columbia University Press.
- Honneth, Axel. 2014d. “Recognition as Ideology: The Connection between Morality and Power.” In *The I in We*. Polity Press.
- Honneth, Axel. 2015. “Rejoinder.” *Critical Horizons* 16 (2): 204–26.
- Honneth, Axel. 2021a. “Intelligibility and Authority in Recognition: A Reply.” In *Recognition and Ambivalence*, edited by Heikki Ikäheimo, Kristina Lepold, and Titus Stahl. Columbia University Press.
- Honneth, Axel. 2021b. “Recognition between Power and Normativity: A Hegelian Critique of Judith Butler.” In *Recognition and Ambivalence*, edited by Heikki Ikäheimo, Kristina Lepold, and Titus Stahl. Columbia University Press.
- hooks, bell. 1984. *Feminist Theory: From Margin to Center*. South End Press.
- Horkheimer, Max. (1937) 1972. “Traditional and Critical Theory.” In *Critical Theory: Selected Essays*. Continuum.

- Hudson, Nicky. 2022. "The Missed Disease? Endometriosis as an Example of 'Undone Science.'" *Reproductive Biomedicine & Society Online* 14 (March): 20–27.
- Husserl, Edmund. (1913) 1962. *Ideas: General Introduction to Pure Phenomenology*. Macmillan Publishing Co.
- Husserl, Edmund. (1936) 1978. *The Crisis of European Sciences and Transcendental Phenomenology: An Introduction to Phenomenological Philosophy*. Translated by David Carr. Northwestern University Press.
- Husserl, Edmund. (1905) 1991. *Collected works. Vol. 4, On the phenomenology of the consciousness of internal time (1893-1917)*. Edited by Rudolf Bernet. Translated by John B. Brough. Nijhoff.
- Husserl, Edmund. (1900–1901) 2001. *Logical Investigations Volume 1*. Edited by Dermot Moran. Routledge.
- Hutchings, Kimberly. 2003. *Hegel and Feminist Philosophy*. Polity Press.
- Hutchings, Kimberly. 2017. "Beauvoir and Hegel." In *A Companion to Simone de Beauvoir*, edited by Nancy Bauer and Laura Hengehold. John Wiley & Sons, Ltd.
- Hutchings, Kimberly, and Tuija Pulkkinen, eds. 2010a. *Hegel's Philosophy and Feminist Thought: Beyond Antigone?* Palgrave Macmillan.
- Hutchings, Kimberly, and Tuija Pulkkinen. 2010b. "Introduction: Reading Hegel." In *Hegel's Philosophy and Feminist Thought: Beyond Antigone?* Breaking Feminist Waves. Palgrave Macmillan.
- Iacovides, Stella, Ingrid Avidon, and Fiona C. Baker. 2015. "What we know about primary dysmenorrhea today: A critical review." *Human Reproduction Update* 21 (6): 762–78.
- Idhe, Don. 1990. *Technology and the Lifeworld: From Garden to Earth*. Indiana University Press.
- Ikäheimo, Heikki. 2022. *Recognition and the Human Life-Form: Beyond Identity and Difference*. Routledge.
- Ikäheimo, Heikki, and Arto Laitinen, eds. 2011. *Recognition and Social Ontology*. Brill Academic Pub.
- Ikäheimo, Heikki, Kristina Lepold, and Titus Stahl, eds. 2021. *Recognition and Ambivalence*. Columbia University Press.
- Inara, Luisa Marin. 2009. "Interview with Axel Honneth - European Journal of Psychoanalysis." *European Journal of Psychoanalysis*, March 12. <https://www.journal-psychoanalysis.eu/articles/interview-with-axel-honneth/>.
- Inwood, M. J. 2005. "Husserl, Edmund." In *The Oxford Companion to Philosophy*, edited by Ted Honderich. Oxford University Press.
- Irigaray, Luce. 1985a. *Speculum of the Other Woman*. Cornell University Press.
- Irigaray, Luce. 1985b. *This Sex Which Is Not One*. Cornell University Press.
- Irigaray, Luce. 2010. "The Eternal Irony of the Community." In *Feminist Readings of Antigone*, edited by Fanny Söderbäck. State University of New York Press.
- Jabr, Fadi I., and Venk Mani. 2014. "An Unusual Cause of Abdominal Pain in a Male Patient: Endometriosis." *Avicenna Journal of Medicine* 4 (4): 99–101.
- Jackson, Bethany, and Deanna E. Telner. 2006. "Managing the Misplaced." *Canadian Family Physician* 52 (11): 1420–24.
- Jeffrey, Sam, Louis Ashton, Tania Ferfolja, and Mike Armour. 2024. "Transgender and Gender Diverse People with Endometriosis: A Perspective on Affirming Gynaecological Care." *Women's Health* 20 (January): 1–7.
- Johnston-Robledo, Ingrid, and Joan C. Chrisler. 2013. "The Menstrual Mark: Menstruation as Social Stigma." *Sex Roles: A Journal of Research* 68 (1–2): 9–18.

- Jones, Cara E. 2015. "Wandering Wombs and 'Female Troubles': The Hysterical Origins, Symptoms, and Treatments of Endometriosis." *Women's Studies* 44 (8): 1083–113.
- Jones, Cara E. 2016. "The pain of endo existence: Toward a feminist disability studies reading of endometriosis." *Hypatia* 31 (3): 554–71.
- Kafer, Alison. 2013. *Feminist, Queer, Crip*. Indiana University Press.
- Käll, Lisa Folkmarson. 2009. "A Being of Two Leaves: On the Founding Significance of the Lived Body." In *Body Claims*, edited by Janne Bromseth, Lisa Folkmarson Käll, and Katarina Mattsson. Centre for Gender Research, Uppsala University.
- Käll, Lisa Folkmarson. 2014. "Reflections on the Ambiguities of Being Post: - Traces of Phenomenology in Judith Butler's «Poststructuralist» Performativity." *Tidskrift för Kjönnsforskning* 38 (3–4): 332–37.
- Käll, Lisa Folkmarson. 2015. "A Path Between Voluntarism and Determinism." *lambda nordica* 20 (2–3): 23–48.
- Käll, Lisa Folkmarson, and Kristin Zeiler, eds. 2014. *Feminist Phenomenology and Medicine*. State University of New York Press.
- Kelly, Molly. 2020. "Estrangement, Epoché, and Performance: Bertolt Brecht's Verfremdungseffekt and a Phenomenology of Spectatorship." *Continental Philosophy Review* 53 (4): 419–31.
- Kuhar, Roman, and David Paternotte. 2017. *Anti-Gender Campaigns in Europe: Mobilizing Against Equality*. Rowman & Littlefield Publishers.
- Lajoie, Corinne. 2019. "Being at Home: A Feminist Phenomenology of Disorientation in Illness." *Hypatia* 34 (3): 546–69.
- Laqueur. 2018. *Making Sex: Body and Gender from the Greeks to Freud*. Harvard University Press.
- Lavee, Einat, and Guy Itzchakov. 2023. "Good Listening: A Key Element in Establishing Quality in Qualitative Research." *Qualitative Research* 23 (3): 614–31.
- Laws, Sophie. 1990. *Issues of Blood: The Politics of Menstruation*. Macmillan.
- Leder, Drew. 1998. "A tale of two bodies." In *Body and flesh: A philosophical reader*, edited by Donn Welton. Blackwell.
- Lindseth, Anders, and Astrid Norberg. 2004. "A Phenomenological Hermeneutical Method for Researching Lived Experience." *Scandinavian Journal of Caring Sciences* 18 (2): 145–53.
- Lindseth, Anders, and Astrid Norberg. 2022. "Elucidating the Meaning of Life World Phenomena. A Phenomenological Hermeneutical Method for Researching Lived Experience." *Scandinavian Journal of Caring Sciences* 36 (3): 883–90.
- Lloyd, Genevieve. 1996. "The Man of Reason." In *Women, Knowledge and Reality. Explorations in Feminist Philosophy*, edited by Ann Garry and Marilyn Pearsall. Routledge.
- LÖF, Löf (Löf regionernas ömsesidiga försäkringsbolag). 2023. "Barnendometriosis.se." [Barnendometriosis.se. https://barnendometriosis.se/](https://barnendometriosis.se/).
- Lorde, Audre. 2007. *Sister Outsider: Essays and Speeches*. Crossing Press.
- Lupton, Deborah. 2003. "The Social Construction of Medicine and the Body." In *The Handbook of Social Studies in Health and Medicine*, edited by Gary L. Albrecht, Ray Fitzpatrick, and Susan C. Scrimshaw. SAGE Publications Ltd.
- Macey, David. 1988. *Lacan in Context*. Verso.
- Malabou, Catherine. 2005. *The Future of Hegel: Plasticity, Temporality, and Dialectic*. Routledge.
- Malinowski, Bronislaw. 1922. *Argonauts of the Western Pacific: An Account of Native Enterprise and Adventure in the Archipelagoes of Melanesian New Guinea*. Routledge & Kegan Paul.
- Malmberg, Denise. 1991. *Skammens röda blomma?: menstruationen och den menstruerande kvinnan i svensk tradition [The Red Flower of Shame? Menstruation and the Menstruating Woman in Swedish Tradition] [Doctoral Dissertation Uppsala University]*. Uppsala University.

- Manderson, Lenore, Narelle Warren, and Milica Markovic. 2008. "Circuit Breaking: Pathways of Treatment Seeking for Women With Endometriosis in Australia." *Qualitative Health Research* 18 (4): 522–34.
- Manen, Max van. 2014. *Phenomenology of Practice: Meaning-Giving Methods in Phenomenological Research and Writing*. Left Coast Press Inc.
- Manen, Max van. 2017a. "But Is It Phenomenology?" *Qualitative Health Research* 27 (6): 775–79.
- Manen, Max van. 2017b. "Phenomenology in Its Original Sense." *Qualitative Health Research* 27 (6): 810–25.
- Mann, Bonnie. 2018a. "Feminist Phenomenology and the Politics of Wonder." *Avant* 9 (2): 43–61.
- Mann, Bonnie. 2018b. "The Difference of Feminist Phenomenology: The Case of Shame." *Puncta* 1 (1): 41–73.
- Marx, Karl. 1843. "Letter from Marx to Arnold Ruge." https://www.marxists.org/archive/marx/works/1843/letters/43_09-alt.htm.
- Mateos, Pablo. 2007. "A Review of Name-Based Ethnicity Classification Methods and Their Potential in Population Studies." *Population, Space and Place* 13 (4): 243–63.
- McNay, Lois. 2008. *Against Recognition*. Polity.
- McNay, Lois. 2015. "Social Freedom and Progress in the Family: Reflections on Care, Gender and Inequality." *Critical Horizons* 16 (2): 170–86.
- McNay, Lois. 2021. "5 Historicizing Recognition: From Ontology to Teleology." In *Recognition and Ambivalence*, edited by Heikki Ikäheimo, Kristina Lepold, and Titus Stahl. Columbia University Press.
- McQueen, Paddy. 2015a. "Honneth, Butler and the Ambivalent Effects of Recognition." *Res Publica* 21 (1): 43–60.
- McQueen, Paddy. 2015b. *Subjectivity, Gender and the Struggle for Recognition*. Palgrave Macmillan UK.
- Mead, Margaret. 2001. *Coming of Age in Samoa: A Psychological Study of Primitive Youth for Western Civilisation*. Perennial Classics.
- Melander, Ida. 2022. *Att göra sin röst hörd: Sjukdomsförhandlande diskurser, genrer och berättelser om endometrios [Making your voice heard. Discourses, genres and narratives in the negotiation of illness] [Doctoral Dissertation Örebro University]*. Studier från Örebro i svenska språke. Örebro University.
- Melander, Ida, and Anders Björkvall. 2022. "När den organiserade sjukvården uppfattas som otillräcklig: Affekt och känsla i texter om endometrios." *RASK - International journal of Language and Communication* 55 (Spring): 33–52.
- Merleau-Ponty, Maurice. (1945) 2012. *Phenomenology of Perception*. Translated by Donald A. Landes. Routledge.
- Mills, Charles W. 1999. *The Racial Contract*. Cornell University Press.
- Mills, Charles W. 2005. "'Ideal Theory' as Ideology." *Hypatia* 20 (3): 165–84.
- Mills, Patricia Jagentowicz. 1986. "Hegel's Antigone." *The Owl of Minerva* 17 (2): 131–52.
- Mills, Patricia Jagentowicz. 1996. *Feminist Interpretations of G.W.F. Hegel*. Pennsylvania State Univ. Press.
- Mirin, Arthur A. 2021. "Gender Disparity in the Funding of Diseases by the U.S. National Institutes of Health." *Journal of Women's Health (2002)* 30 (7): 956–63.
- Moberg, Christian. 2017. *The Human Endometrium: Studies on Angiogenesis and Endometriosis*. Acta Universitatis Upsaliensis.
- Moderaterna. 2022. "Överenskommelse för Sverige [Tidö Agreement]." *Moderaterna*, October 14. <https://moderaterna.se/nyhet/overenskommelseforsverige/>.

- Montgomery, Rita E. 1974. "A Cross-Cultural Study of Menstruation, Menstrual Taboos, and Related Social Variables." *Ethos* 2 (2): 137–70.
- Moran, Dermot. 2019. "Husserl's Phenomenology of Spirit: A Reading of the Crisis of European Sciences and Related Manuscripts." In *Hegel and Phenomenology*, edited by Alfredo Ferrarin, Dermot Moran, Elisa Magri, and Danilo Manca. Contributions to Phenomenology. Springer International Publishing.
- Morse, Janice. 2020. "The Changing Face of Qualitative Inquiry." *International Journal of Qualitative Methods* 19: 1–7.
- Mostowlansky, Till, and Andrea Rota. 2020. "Emic and Etic." *Cambridge Encyclopedia of Anthropology*, ahead of print. <https://doi.org/10.29164/20emicetic>.
- Mulinari, Diana. 1999. "Vi tar väl kvalitativ metod - det är så lätt." In *Mer än kalla fakta*, edited by Katarina Sjöberg. Studentlitteratur.
- Natanson, Maurice. 1973. *Edmund Husserl: Philosopher of Infinite Tasks*. Northwestern University Studies in Phenomenology & Existential Philosophy. Northwestern University Press.
- National Board of Health and Welfare, [Socialstyrelsen]. 2018. *Nationella riktlinjer för vård vid endometrios*.
- Neugebauer, Christian M. 1990. "The Racism of Hegel and Kant." In *Sage Philosophy*. Brill.
- Neuhouser, Frederick. 2008. *Rousseau's Theodicy of Self-Love: Evil, Rationality, and the Drive for Recognition*. Oxford University Press.
- Nilsson, Ulrika. 2005. *Det Heta Könet: Gynekologin i Sverige Kring Förra Sekelskiftet*. Wahlström & Widstrand.
- Nussbaum, Martha. 1988. *Nature, Function, and Capability: Aristotle on Political Distribution*. Oxford Studies in Ancient Philosophy. Oxford University Press.
- Nussbaum, Martha. 1992. "Human Functioning and Social Justice: In Defense of Aristotelian Essentialism." *Political Theory* 20 (2): 202–46.
- Nussbaum, Martha. 2000. *Women and Human Development: The Capabilities Approach*. Cambridge University Press.
- Nussbaum, Martha, and Amartya Sen. 1993. *The Quality of Life*. Oxford University Press.
- Nyström, Anna. 2022. "Judith Butler och det sörjande självets kapacitet till icke-väld – influenser från Sigmund Freud och Melanie Klein." *Tidskrift för genusvetenskap* 43 (2–3).
- Oakley, Ann. 1981. "Interviewing Women: A Contradiction in Terms." In *Doing Feminist Research*, edited by Helen Roberts. Routledge & Kegan Paul.
- Oakley, Ann. 1993. *Essays on Women, Medicine and Health*. Edinburgh University Press.
- Oakley, Ann. 2016. "Interviewing Women Again: Power, Time and the Gift." *Sociology* 50 (1): 195–213.
- Oikkonen, Venla, and Elina Helosvuori. 2024. "Living with Acuteness in Chronic Illness: The Temporal Underpinnings of Endometriosis." *Medical Anthropology Quarterly*, December 28.
- Okita, F., M. Abrao, L. a. S. Lara, M. P. Andres, C. Cunha, and L. G. Oliviera Brito. 2021. "Endometriosis in Transgender Men – a Systematic Review with Metanalysis." *Journal of Minimally Invasive Gynecology* 28 (11): S103–4.
- Oksala, Johanna. 2004. "What is feminist phenomenology? Thinking birth philosophically." *Radical Philosophy* 2004 (126): 16–22.
- Oksala, Johanna. 2016. *Feminist Experiences: Foucauldian and Phenomenological Investigations*. Northwestern University Press.
- Oksala, Johanna. 2023. "The Method of Critical Phenomenology: Simone de Beauvoir as a Phenomenologist." *European Journal of Philosophy* 31 (1): 137–50.

- Peirce, Charles S. 1957. *Essays in the Philosophy of Science*. Edited by Vincent Tomas. Liberal Arts Press.
- Persdotter, Josefin. 2022. *Menstrual Dirt: An Exploration of Contemporary Menstrual Hygiene Practices in Sweden*. Göteborgs universitet.
- Picht, Johannes. 2022. "Repetition and Breakdown: Freud, Winnicott, and Death." *The International Journal of Psychoanalysis* 103 (4): 619–38.
- Plato. 1921. *Theaetetus*. Translated by Harold North Fowler. Harvard University Press.
- Ploug, Anna Cornelia. 2024. "Mermaid Dialectics: The Concrete Method of 'The Second Sex.'" *Simone de Beauvoir Studies* 34 (2): 335–56.
- Ploug, Anna Cornelia. Forthcoming. "Other." In *Understanding Beauvoir, Understanding Modernism*, edited by Pauline Henri-Tierney. Bloomsbury Press.
- Puncta: Journal of Critical Phenomenology. 2025. "Puncta." <https://puncta.journals.villanova.edu/>.
- Rawls, John. 1971. *A Theory of Justice*. Harvard University Press.
- Rea, Teresa, Pierluigi Giampaolino, Silvio Simeone, Gianluca Pucciarelli, Rosaria Alvaro, and Assunta Guillari. 2020. "Living with Endometriosis: A Phenomenological Study." *International Journal of Qualitative Studies on Health and Well-Being* 15 (1): 1822621.
- Reynolds, Jack. 2023. "Phenomenology, Abduction, and Argument: Avoiding an Ostrich Epistemology." *Phenomenology and the Cognitive Sciences* 22 (3): 557–74.
- Roberts-Garratt, Oliver. 2024. "Foucault's Hegel Thesis: The 'Tragic Destiny' of Life and the 'Being-There' of Consciousness." *Foucault Studies* 36 (1): 443–69.
- Robstad, Nastasja, Anita Paulsen, Ingvild Vistad, et al. 2024. "Experiences of Pain Communication in Endometriosis: A Meta-Synthesis." *Acta Obstetrica et Gynecologica Scandinavica*.
- Rodemeyer, Lanei M. 2022. "A Phenomenological Critique of Critical Phenomenology." In *Phenomenology as Critique*. Routledge.
- Rose, A. M. 1945. "A Research Note on Experimentation in Interviewing." *American Journal of Sociology* 51: 143–44.
- Salamon, Gayle. 2018. "What's Critical about Critical Phenomenology?" *Puncta: Journal of Critical Phenomenology* 1 (1): 8–17.
- Santulli, Pietro, Silvia Vannuccini, Mathilde Bourdon, Charles Chapron, and Felice Petraglia. 2025. "Adenomyosis: The Missed Disease." *Reproductive Biomedicine Online* 50 (4): 104837.
- Saunders, Benjamin, Jenny Kitzinger, and Celia Kitzinger. 2015. "Anonymising Interview Data: Challenges and Compromise in Practice." *Qualitative Research* 15 (5): 616–32.
- SBU, [Swedish Agency for Health Technology Assessment and Assessment of Social Service]. 2018. *Endometriös - diagnostik, behandling och bemötande: En systematisk översikt och utvärdering av medicinska, hälsoekonomiska, sociala och etiska aspekter (Endometriosis – Diagnosis, treatment and patient experiences A systematic review and assessment of medical, economic, social and ethical aspects)*. SBU-rapport 277. SBU. <https://www.sbu.se/277>.
- Schrodt, G. R., M. O. Alcorn, and J. Ibanez. 1980. "Endometriosis of the Male Urinary System: A Case Report." *The Journal of Urology* 124 (5): 722–23.
- Secosan, Cristina, Liga Balulescu, Simona Brasoveanu, et al. 2020. "Endometriosis in Menopause - Renewed Attention on a Controversial Disease." *Diagnostics* 10 (3): 134.
- Seear, Kate. 2009a. "'Nobody Really Knows What It Is or How to Treat It': Why Women with Endometriosis Do Not Comply with Healthcare Advice." *Health, Risk & Society* 11 (4): 367–85.

- Seear, Kate. 2009b. "‘Standing up to the Beast’: Contradictory Notions of Control, Un/Certainty and Risk in the Endometriosis Self-Help Literature." *Critical Public Health* 19 (1): 45–58.
- Seear, Kate. 2009c. "The Etiquette of Endometriosis: Stigmatisation, Menstrual Concealment and the Diagnostic Delay." *Social Science & Medicine* 69 (8): 1220–27.
- Seear, Kate. 2014. *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*. Ashgate.
- Sen, Amartya. 1980. "Equality of What?" In *Tanner Lectures on Human Values, Volume 1*, edited by S. McMurrin. Cambridge University Press.
- Sen, Amartya. 1985. *Commodities and Capabilities*. North-Holland.
- Sen, Amartya. 2009. *The Idea of Justice*. Penguin Books.
- Sen, Amartya. 2020. *Development as Freedom*. Vintage Books.
- Shah, Divya K., Molly B. Moravek, Anjel Vahratian, Vanessa K. Dalton, and Dan I. Lebovic. 2010. "Public Perceptions of Endometriosis: Perspectives from Both Genders." *Acta Obstetrica Et Gynecologica Scandinavica* 89 (5): 646–50.
- Shildrick, Margrit. 2009. *Dangerous Discourses of Disability, Subjectivity and Sexuality*. Palgrave Macmillan.
- Shohat, Ella. 1992. "‘Lasers for ladies’: Endo discourse and the inscriptions of science." *Camera Obscura: Feminism, Cultural and Media Studies* 10 (2 (29)): 57–90.
- Showalter, Elaine. 1987. *The Female Malady: Women, Madness and English Culture, 1830-1980*. Virago Press.
- Simoens, Steven, Gerard Dunselman, Carmen Dirksen, et al. 2012. "The Burden of Endometriosis: Costs and Quality of Life of Women with Endometriosis and Treated in Referral Centres." *Human Reproduction* 27 (5): 1292–99.
- Sims, Omar T., Jhumka Gupta, Stacey A. Missmer, and Irene O. Aninye. 2021. "Stigma and Endometriosis: A Brief Overview and Recommendations to Improve Psychosocial Well-Being and Diagnostic Delay." *International Journal of Environmental Research and Public Health* 18 (15): 8210.
- Skeggs, Beverley. 1995. "Theorising, Ethics and Representation in Feminist Ethnography." In *Feminist Cultural Theory: Process and Production*. Manchester University Press.
- Skeggs, Beverley. 2001. "The Toilet Paper: Femininity, Class and Mis-Recognition." *Women’s Studies International Forum* 24 (3): 295–307.
- Slatman, Jenny. 2014. "Multiple Dimensions of Embodiment in Medical Practices." *Medicine, Health Care and Philosophy* 17 (4): 549–57.
- Smith, Jonathan A., Paul Flowers, and Michael Larkin. 2009. *Interpretative Phenomenological Analysis: Theory, Method and Research*. Sage.
- Söderbäck, Fanny. 2010. *Feminist Readings of Antigone*. State University of New York Press.
- Spelman, Elizabeth V. 1982. "Woman as Body: Ancient and Contemporary Views." *Feminist Studies* 8 (1): 109–31.
- Stein, Edith. 2017. *Essays on Woman*. Second edition, Revised. Edited by Lucy Gelber and Romaeus Leuven. Translated by Freda Mary Oben. The Collected Works of Edith Stein. ICS Publications.
- Surrey, Eric S., Ahmed M. Soliman, Scott J. Johnson, Matthew Davis, Jane Castelli-Haley, and Michael C. Snabes. 2018. "Risk of Developing Comorbidities Among Women with Endometriosis: A Retrospective Matched Cohort Study." *Journal of Women’s Health* 27 (9): 1114–23.
- Svenaeus, Fredrik. 2000. *The Hermeneutics of Medicine and the Phenomenology of Health: Steps Towards a Philosophy of Medical Practice*. Springer.

- Swedberg, Richard. 2012. "Theorizing in Sociology and Social Science: Turning to the Context of Discovery." *Theory and Society* 41 (1): 1–40.
- Swedish Research Council. 2019. "CODEX - Rules and Guidelines for Research." <http://www.codex.vr.se/en/index.shtml>.
- Swedish Research Council. 2023. "New Mapping of Research Needs in Women's Health - Swedish Research Council." Vetenskapsrådet. <https://www.vr.se/english/just-now/news/news-archive/2023-12-19-new-mapping-of-research-needs-in-womens-health.html>.
- Taylor, Charles. 1994. *Multiculturalism: Examining the Politics of Recognition*. Edited by Amy Gutmann. Princeton University Press.
- The Economist Group. 2025. "Sweden Surpasses Iceland as the Best Place to Be a Working Woman, According to The Economist's 2025 Glass-Ceiling Index." <https://www.economistgroup.com/press-centre/the-economist/sweden-surpasses-iceland-as-the-best-place-to-be-a-working-woman-according>.
- The Guardian*. 2014. "The Guardian View on a Year in Feminism: 2014 Was a Watershed [Editorial]." Opinion. December 31. <https://www.theguardian.com/commentis-free/2014/dec/31/guardian-view-year-feminism-2014-watershed>.
- The Lancet Obstetrics, Gynaecology. 2025. "Endometriosis: From Awareness to Action." *The Lancet Obstetrics, Gynaecology, & Women's Health* 1 (3): e149.
- The Local Sweden. 2017. "Sweden World's Best Country for Women: Ranking." The Local Sweden, March 8. <https://www.thelocal.se/20170308/sweden-worlds-best-country-for-women-report>.
- Thwaites, Rachel. 2017. "(Re)Examining the Feminist Interview: Rapport, Gender 'Matching,' and Emotional Labour." *Frontiers in Sociology* 2 (13).
- Trigg, Dylan. 2021. "‘It Happens, But I’m Not There’: On the Phenomenology of Child-birth." *Human Studies* 44 (4): 615–33.
- Tugendhat, Ernst. 1989. *Self-Consciousness and Self-Determination*. Translated by Paul Stern. Studies in Contemporary German Social Thought, edited by Thomas McCarthy. MIT Press.
- UN Women. 2025. "Democratic Backsliding and the Backlash against Women's Rights: Understanding the Current Challenges for Feminist Politics." UN Women – Headquarters, March 6. <https://www.unwomen.org/en/digital-library/publications/2020/06/discussion-paper-democratic-backsliding-and-the-backlash-against-womens-rights>.
- UNDP. 2016. "The Capability Approach and Human Development: Some Reflections." In *Human Development Reports*. United Nations Development Programme. <https://hdr.undp.org/content/capability-approach-and-human-development-some-reflections>.
- United Nations. 1948. "Universal Declaration of Human Rights." United Nations, United Nations. <https://www.un.org/en/about-us/universal-declaration-of-human-rights>.
- Ussher, Jane M. 2005. *The Madness of Women: Myth and Experience*. Taylor & Francis Group.
- Vatanen, Katja. 2017. "Ingen ska behöva vänta i åtta år på att få en diagnos." *Dagens ETC*, March 24. <https://www.etc.se/debatt/ingen-ska-behova-vanta-i-atta-ar-pa-att-fa-en-diagnos>.
- Venkatapuram, Sridhar. 2011. *Health Justice: An Argument from the Capabilities Approach*. Polity.
- Waldenfels, Bernhard. 1990. "Experience of the Alien in Husserl's Phenomenology." *Research in Phenomenology* 20 (January): 19–33.

- Weber, Max. (1970) 2013. "Science as a Vocation." In *From Max Weber: Essays in Sociology*, edited by H. H. Gerth and Wright Mills. Routledge.
- Weiss, Gail. 2008. *Refiguring the Ordinary*. Indiana University Press.
- Weiss, Gail. 2014. "The Myth of Woman Meets the Myth of Old Age An Alienating Encounter with the Aging Female Body." In *Simone de Beauvoir's Philosophy of Age: Gender, Ethics, and Time*, edited by Silvia Stoller. De Gruyter.
- Weiss, Gail. 2017. "The 'Normal Abnormalities' of Disability and Aging: Merleau-Ponty and Beauvoir." In *Feminist Phenomenology Futures*, edited by Helen A. Fielding and Dorothea E. Olkowski. Indiana University Press.
- Weiss, Gail, Gayle Salamon, and Ann V. Murphy, eds. 2019. "Introduction: Transformative Descriptions." In *50 Concepts for a Critical Phenomenology*. Northwestern University Press.
- Welton, Donn, and Hugh J. Silverman, eds. 1987. *Critical and Dialectical Phenomenology*. State University of New York Press.
- Westergaard, David, Pope Moseley, Freja Karuna Hemmingsen Sørup, Pierre Baldi, and Søren Brunak. 2019. "Population-Wide Analysis of Differences in Disease Progression Patterns in Men and Women." *Nature Communications* 10 (1): 666.
- Whelan, Emma. 2007. "No One Agrees except for 'Those of Us Who Have It': Endometriosis Patients as an Epistemological Community." *Sociology of Health & Illness* 29 (7): 957–82.
- WHO. 2019a. "WHO | Equity." World Health Organization. <https://www.who.int/gender-equity-rights/understanding/equity-definition/en/>.
- WHO. 2019b. "WHO | Ethical Standards and Procedures for Research with Human Beings." World Health Organization. <https://www.who.int/ethics/research/en/>.
- WHO. 2019c. "WHO | Gender." World Health Organization. <http://www.who.int/gender-equity-rights/understanding/gender-definition/en/>.
- WHO. 2025. "WHO | Endometriosis." World Health Organization. <https://www.who.int/news-room/fact-sheets/detail/endometriosis>.
- Williams, Robert R. 1992. *Recognition: Fichte and Hegel on the Other*. State University of New York Press.
- Winkler, Inga T., Pema Lhaki, and Sara E. Baumann. 2024. "Its Manifestations May Vary, but Menstrual Stigma Is Universal." *Women's Health* 20 (January): 1–3.
- Wolff, Jonathan. 2015. "Social Equality, Relative Poverty and Marginalised Groups." In *The Equal Society: Essays on Equality in Theory and Practice*, edited by George Hull. Lexington Books.
- Wolff, Jonathan, and Avner de-Shalit. 2007. *Disadvantage*. Oxford University Press.
- World Economic Forum. 2025. "Gender Gap Report 2025." World Economic Forum. <https://www.weforum.org/publications/global-gender-gap-report-2025/>.
- Worldwide EndoMarch. 2024. "Who We Are." *Worldwide EndoMarch*. <https://endomarch.org/about-endometriosis/who-we-are/>.
- Young, Iris Marion. 1997. "Unruly Categories: A Critique of Nancy Fraser's Dual Systems Theory." *NEW LEFT REVIEW*, no. 222: 147–60.
- Young, Iris Marion. 2005a. "House and Home: Feminist Variations on a Theme." In *On Female Body Experience: "Throwing like a Girl" and Other Essays*. Oxford University Press.
- Young, Iris Marion. 2005b. *On Female Body Experience: "Throwing like a Girl" and Other Essays*. Oxford University Press.
- Young, Iris Marion. 2007. "Recognition of Love's Labor: Considering Axel Honneth's Feminism." In *Recognition and Power: Axel Honneth and the Tradition of Critical Social Theory*, by Bert van den Brink and David Owen. Cambridge University Press.
- Young, Iris Marion. 2011. *Justice and the Politics of Difference*. Princeton University Press.

- Young, Kate, Jane Fisher, and Maggie Kirkman. 2015. "Women's Experiences of Endometriosis: A Systematic Review and Synthesis of Qualitative Research." *The Journal Of Family Planning And Reproductive Health Care* 41 (3): 225–34. 25183531.
- Zahavi, Dan. 2005. *Subjectivity and selfhood: Investigating the first-person perspective*. MIT Press.
- Zahavi, Dan. 2011. "The Experiential Self: Objections and Clarifications." In *Self, No Self? Perspectives from Analytical, Phenomenological, and Indian Traditions*. Oxford University Press.
- Zahavi, Dan. 2015. "You, Me, and We: The Sharing of Emotional Experiences." *Journal of Consciousness Studies* 22 (1–2): 84–101.
- Zahavi, Dan. 2019a. "Getting It Quite Wrong: Van Manen and Smith on Phenomenology." *Qualitative Health Research* 29 (6): 900–907.
- Zahavi, Dan. 2019b. *Phenomenology: The Basics*. First edition. Routledge.
- Zahavi, Dan. 2021. "Applied Phenomenology: Why It Is Safe to Ignore the Epoché." *Continental Philosophy Review* 54 (2): 259–73.
- Zahavi, Dan. 2025. "Critical and Political Phenomenology." In *Phenomenology: The Basics*. Routledge.
- Zala, Miklós, Simon Rippon, Tom Theuns, Sem de Maagt, and Bert van den Brink. 2020. "From Political Philosophy to Messy Empirical Reality." In *Justice and Vulnerability in Europe: An Interdisciplinary Approach*, edited by Trudie Knijn and Dorota Lepianka. Edward Elgar. Scopus.
- Zurn, Christopher F. 1997. "The Normative Claims of Three Types of Feminist Struggles for Recognition." *Philosophy Today* (Charlottesville, United States) 41: 73–78.

APPENDIX

Appendix I: Information Letter (in Swedish)



Stockholms
universitet

2018-02-01

1 (2)

Ina Hallström
Doktorand i genusvetenskap
Institutionen för etnologi, religionshistoria
och genusvetenskap

Forskningsprojekt om erfarenheter av endometrios. Vill du delta?

Mitt namn är Ina Hallström och jag är doktorand i genusvetenskap vid Stockholms universitet. Jag söker personer som skulle vilja delta i en intervju inom ramen för mitt avhandlingsarbete som handlar om erfarenheter av sjukdomen endometrios.

Jag söker dig som:

- Är minst 18 år
- Har fått diagnosen endometrios

Endometrios är en vanlig sjukdom som drabbar ungefär var tionde person som har menstruation. Ändå saknas det idag nationella riktlinjer för vård av endometrios i Sverige och vägen till diagnos och vård är många gånger lång. Trots dessa problem så saknas forskning i Sverige om hur endometriossjuka själva upplever sin situation. I mitt forskningsprojekt vill jag därför undersöka erfarenheter av endometrios och hur erkännande av sjukdomen spelar roll. Fokus för studien är egna erfarenheter av endometrios, det kan handla om kontakter med vården, möjligheten till diagnos, hantering av smärta, hur sjukdomen påverkar relationen till skola och arbetsliv och till nära och kära. För mig är det viktigt att undersöka möjligheterna till vård och stöd när man lever med en kronisk sjukdom som inte alltid syns utpå. Jag är också intresserad av hur normer kring kön och andra maktordningar påverkar möjligheten till vård och jämlika livsvillkor. Genom ditt deltagande kan du bidra till att öka kunskapen inom detta viktiga område.

Om intervjuerna

Ditt deltagande är helt frivilligt och du bestämmer själv tid och plats för intervjun, hemma hos dig eller på en annan plats där du känner dig bekväm. Under intervjun kommer jag att be dig berätta om dina erfarenheter av sjukdomen, du väljer själv vad du vill dela med dig av. Intervjun kommer att vara ca 1,5-2 timmar och ljudet spelas in av mig. Din medverkan i studien kommer att vara anonym och du kan när som helst, utan särskild förklaring, välja att avbryta din medverkan.

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Sekretess och hantering av material

Avhandlingsprojektet följer Vetenskapsrådets etiska principer och har gått igenom etisk prövning. Materialet från intervjuerna kommer att behandlas så att inga obehöriga kan ta del av det. Efter projektets avslutande arkiveras både det inspelade och skrivna materialet i tio år i enlighet med arkivlagen och Stockholms universitets bestämmelser. Endast behöriga personer har tillgång till materialet under denna tid. Din medverkan är anonym vilket innebär att jag fingerar namn, ålder, bostadsort och andra personuppgifter som skulle kunna användas för att identifiera dig. En kodlista som är otillgänglig för obehöriga upprättas där ett fingerat namn motsvarar en intervjuperson i materialet. Forskningsprojektet kommer att publiceras i form av en avhandling och artiklar i svenska och internationella vetenskapliga tidskrifter. Om du vill läsa utskrifterna av intervjun så får du möjlighet att göra det.

Jag hoppas du vill delta i en intervju!

Om du vill delta eller har några frågor, hör av dig till mig:

Ina Hallström
Doktorand i genusvetenskap
Institutionen för etnologi, religionshistoria och genusvetenskap

ina.hallstrom@gender.su.se

Tel: 08-674 71 33

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106 91 Stockholm

Du kan också kontakta mina handledare:

Annika Olsson, annika.olsson@gender.su.se

Lisa Käll, lisa.kall@gender.su.se



2018-06-11

Ina Hallström
Doktorand i genusvetenskap
Institutionen för etnologi, religionshistoria
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Information om projektet: "En studie av erkännandets roll för den levda erfarenheten av endometrios"

Bakgrund och syfte

Endometrios är en vanlig sjukdom som drabbar ungefär var tionde person som har menstruation. Ändå saknas det idag nationella riktlinjer för vård av endometrios i Sverige och vägen till diagnos och vård är många gånger lång. Trots dessa problem så saknas forskning i Sverige om hur endometriossjuka själva upplever sin situation. I mitt forskningsprojekt vill jag därför undersöka erfarenheter av endometrios och hur erkännande av sjukdomen spelar roll. Fokus för studien är egna erfarenheter av endometrios, det kan handla om kontakter med vården, möjligheten till diagnos, hantering av smärta, hur sjukdomen påverkar relationen till skola och arbetsliv och till nära och kära. För mig är det viktigt att undersöka möjligheterna till vård och stöd när man lever med en kronisk sjukdom som inte alltid syns utanpå. Jag är också intresserad av hur normer kring kön och andra maktordningar påverkar möjligheten till vård och jämlika livsvillkor.

Vill du delta?

Jag vänder mig till dig för att höra om du är intresserad av att medverka i en intervju inom ramen för forskningsprojektet. Jag vill gärna ta del av dina erfarenheter och tankar om att leva med endometrios. Ditt deltagande är helt frivilligt och du bestämmer själv tid och plats för intervjun, hemma hos dig eller på en annan plats där du känner dig bekväm. Under intervjun kommer jag att be dig berätta om dina erfarenheter av sjukdomen, du väljer själv vad du vill dela med dig av. Intervjun kommer att vara ca 1,5-2 timmar och ljudet spelar in av mig. Din medverkan i studien kommer att vara anonym och du kan när som helst, utan särskild förklaring, välja att avbryta din medverkan.

Sekretess och hantering av material

Avhandlingsprojektet följer Vetenskapsrådets etiska principer och har gått igenom etisk prövning. Materialet från intervjuerna kommer att behandlas så att inga obehöriga kan ta del av det. Efter projektets avslutande arkiveras både det inspelade och skrivna materialet i tio år i

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enlighet med arkivlagen och Stockholms universitets bestämmelser. Endast behöriga personer har tillgång till materialet under denna tid. Forskningsprojektet kommer att publiceras i form av en avhandling och artiklar i svenska och internationella vetenskapliga tidskrifter. Citat från dig kan komma att användas i avhandlingstexten men det kommer inte vara möjligt att koppla uppgifterna till din person då du anonymiseras i texten. Din medverkan är anonym vilket innebär att jag fingerar namn, ålder, bostadsort och andra personuppgifter som skulle kunna användas för att identifiera dig. En kodlista som är otillgänglig för obehöriga upprättas där ett fingerat namn motsvarar en intervjuperson i materialet. Om du vill läsa utskrifterna av intervjun så får du möjlighet att göra det. Ansvarig för hanteringen av dina personuppgifter är Stockholms universitet. Studien kommer bedrivas i enlighet med Dataskyddsförordningen (GDPR, The General Data Protection Regulation) och du har rätt att en gång per kalenderår gratis ta del av de uppgifter som finns lagrade om dig och vid behov få uppgifterna raderade eller raderade.

Kontakt

Om du har några frågor eller funderingar är du välkommen att kontakta mig eller mina handledare.

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Samtycke för deltagande i intervjustudie

Härmed intygas att jag väljer att delta i projektet: "En studie av erkännandets roll för den levda erfarenheten av endometrios".

Jag har erhållit muntlig och skriftlig information angående projektet.

Alla personuppgifter samt inspelningen av intervjun kommer att behandlas konfidentiellt. Jag har haft möjlighet att ställa frågor och är medveten om att jag när som helst har möjlighet att avbryta mitt deltagande.

Ort

Datum

Namnteckning

Namnförtydligande

Appendix III: Interview Guide (in Swedish)

Historik

Kan du berätta om när du började du få symptom?

Diagnos

Hur gick det till att få diagnos?

Vård

Hur har vården fungerat?

Hur har bemötande från vården varit?

Smärta och symptom

Kan du berätta om smärta och symptom?

Familj och vänner

Hur har familj och vänner hanterat det?

Skola/arbete

Hur har det påverkat skola/arbetsliv?

Peer-support

Har du kontakt med andra som har sjukdomen?

Följer du några grupper/konton på nätet? Delar du själv erfarenheten på nätet?