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Endo Time: Endometriosis and the Flow of Recognition

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Abstract

The relation between time and gender has been extensively discussed in feminist theory, from Simone de Beauvoir to recent studies of queer temporality and crip time. In this article, I explore gender as “lived time” in relation to a pressing feminist issue: social recognition of the chronic illness endometriosis (endo). Based on my interviews with individuals diagnosed with endo, I argue that lived time can be studied by approaching becoming as a dynamic process or flow of recognition, creating certain temporal patterns in the lifeworld. I propose the concept of “endo time” as a phenomenological conception of the lived time of endo. I identify three temporal patterns that characterize endo time: waiting time (I), cyclical or chronic time (II), and sedimented time (III). The analysis contributes to feminist philosophy by detailing how gender appears as a specific orchestration of time. Because of its connection to feminized pain and menstrual flow on the one hand and social recognition on the other, endo presents an illuminating case for exploring the relation between gender, recognition, and lived time.

How might time be considered a question of gender justice? My starting point in this text is a pressing feminist issue: social recognition of the painful chronic illness endometriosis—or *endo*.¹ Based on an interview study on endo in Sweden, I explore how social recognition of the condition appears in the lifeworld as a specific orchestration of time, what I call *endo time*. The interviews analyzed here are part of a larger study where I explore experiences and recognition of endo in Sweden, a country often heralded as a gender equality utopia and with a self-declared “first feminist government in the world.”² I have conducted in-depth interviews with 15 individuals diagnosed with endo, ranging from 18 to 62 years old and coming from different parts of the country. All interviewees but one are cisgender, and a majority are heterosexual.³ During the course of the interviews, it became clear that time shaped endo experiences in a myriad of ways—and in turn, endo shaped the experience of time. Endo affected everything from relationships with significant others to education and working life

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and, hence, interviewees' plans and projects for the future. Even so, temporality has not been made an explicit theme for exploring endo experience. Neither has recognition, even though the difficulties in receiving diagnosis, healthcare, and support are by now well-documented (Ballard et al. 2006; Jones 2015; Seear 2009; Shah et al. 2010).

Endometriosis is defined as a chronic condition where tissue similar to the lining of the uterus (the endometrium) grows outside it and onto pelvic organs. The most common symptoms are severe pain and subfertility. Despite descriptions of the condition since the 1860s, the etiology is unknown, and there is still no cure (Giudice and Kao 2004).⁴ There is a well-described international “delay” in diagnosis of up to ten years (Ballard et al. 2006; Denny 2011). Affecting one in ten of menstruators worldwide, recognition of endo is increasingly being articulated as a political issue. The founders of the Worldwide EndoMarch describe it as a condition “affecting an estimated 200 million women, girls, and transgender individuals around the world and topping the list as one of the most urgent, yet ignored public health emergencies of our era” (Worldwide EndoMarch 2019).

Feminist phenomenology has been concerned with many neighboring topics, such as lived experience of menstruation and female embodiment (Beauvoir 1949/1988; Young 2005), illness and pain (Fisher 2014; Käll 2012; Käll and Zeiler 2014), and temporality (Fielding et al. 2011)—but not with endo specifically. Moreover, as Cara E. Jones notes, the “absence of endometriosis in feminist disability theorizing is particularly troubling given the gendered nature of the disease” (Jones 2016, 555). The present text is a partial answer to her call that feminist disability studies should theorize endometriosis and, as I would like to add, feminist phenomenology should do so as well since it is an underexplored phenomenon located precisely at the crossroad of gender and illness experience.

Because of its connection to feminized pain and menstrual flow on the one hand and social recognition and responses on the other, endo presents an illuminating case for exploring the relation between gender, recognition, and lived time, which may have a broader resonance. In this endeavor, I am guided by the 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? Below, I propose the concept of *endo time* for understanding the entanglement of gender, recognition, and lived time in endo experience. 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.

Endo time and gender as lived time

The relation between time and gender has been extensively discussed throughout the history of feminist theory.⁵ In *The second sex*, Simone de Beauvoir describes men as being characterized by transcendence and by the ability to realize their aims and projects in *linear time* and history. Women, on the other hand, are confined to immanence, repetition, and *cyclical time*: “woman clings to routine, time has for her no element of novelty, it is not a creative flow; because she is doomed to repetition, she sees in the future only a duplication of the past” (Beauvoir 1949/1988, 610). But, as Fanny Söderbäck notes, both cyclical time and linear time make change impossible by either repeating or repressing the past (Söderbäck 2019). Does this mean that Beauvoir got time wrong? Not necessarily. It all depends on what we mean by time. Starting off

from a rereading of Beauvoir and recent discussions of gender and time, I suggest a return to Edmund Husserl's phenomenology of time to arrive at a clearer understanding of what we mean when we talk about time and notions such as becoming. After this clarification, I move on to the notion of *endo time* and how I conceptualize the lived time of endo experience using the notion of recognition.

Megan M. Burke's (2018) rereading of Beauvoir provides a fruitful point of departure that reaches beyond the distinction between linear and cyclical time. Burke proposes that Beauvoir's *The second sex* offers a feminist phenomenology of temporality, even though it is seldom described as such⁶—and a useful account of *gender as lived time*.⁷ The main argument is that if we pay attention to temporality as a central theme in Beauvoir's description of becoming woman, gender and temporality are portrayed as co-constitutive phenomena. For example, Beauvoir writes: "the woman protests against this long wait that is her own life. In one sense, *her whole existence is a waiting*" (Beauvoir quoted in Burke 2018, 112). Burke suggests that Beauvoir understands *the temporality of waiting*, or a passive present, to be an underlying structure of women's existence and subordination. Expanding on the famous statement, "One is not born, but rather becomes, a woman," Burke emphasizes that Beauvoir's notion of becoming refers to a phenomenological understanding where human existence is never simply static or given, but an open ongoing process (Burke 2018, 112). Becoming woman does not merely indicate a process of acquisition that unfolds in time but a way of acting and assuming a world—a mode of being that is realized as lived time.

After Beauvoir, contemporary thinkers have repeated a similar line of criticism—*for us, time is not a creative flow!*—and have sought to theorize temporalities going against the grain, such as Denise Riley's *Time lived, without its flow* (2019), Heather Love's *Feeling backwards* (2007), Elizabeth Freeman's and Jack Halberstam's discussions of *queer temporality* (Freeman 2010; Halberstam 2005), and Alison Kafer's discussion of *crip time* (2013). This has sometimes been done while simultaneously expressing hesitation towards concepts such as "flow" and "becoming." A prime example is Lisa Baraitser's influential account in *Enduring time* (Baraitser 2017), a book devoted to "time's suspension" in experiences like waiting, staying, delaying, or enduring. Baraitser argues that in these kinds of experiences when it feels like nothing is changing and life is neither eventful nor vital, a philosophy of "becoming"⁷ simply does not help (Baraitser 2017, 13). There is a tension, however, which is evident when Baraitser adds the following caveat: "I doubt I could possibly sustain a position in which I too did not agree that all matter is in motion, that stasis is incompatible with life (...) [but] I do not believe that anyone *lives* a philosophy of becoming (...). I rarely feel like a teaming flux of vibrant matter, even if I can see that this is what I am" (Baraitser 2017, 13). Instead of becoming, Baraitser suggests a focus on "lived experience." In effect, she makes a distinction between two different notions of time which could be called the *ontology of time* (becoming) versus the *experience of time* ("lived experience"). I want to propose that these two positions are not the incompatibles that Baraitser suggests.

A return to Husserl's analysis of time is instructive and will clarify my own position which is that notions such as "flow," "flux," and "becoming" actually underpin a phenomenology of time—but they do not necessarily imply the optimism that Baraitser and others react against. The concept of "lived experience" (*Erlebnis*) has become commonplace today but was first extensively studied in the phenomenology of Husserl and is not distinct from the ontology of time. Husserl regarded the enigma of

time as the “most difficult” (Husserl 1905/1991, 286), yet “most important” (346) of all phenomenological problems. It has been argued that no other philosopher has been as determined or prolific in making sense of temporality.⁸ For Husserl, time belongs essentially to experience as such, an insight captured in his recurrent use of the metaphor of a “flow” or “stream” of experience:

Every real experience (...) is necessarily one that endures; and with this duration it takes its place within an endless continuum of durations—a concretely filled continuum. It necessarily has a temporal purview concretely filled, and stretching away endlessly on all sides. And that at once tells us that it belongs to *one* endless “stream of experience.” (Husserl 1913/2014, 236)

The time Husserl has in mind is a phenomenological lived time constituted by “this unitary form of all experiences within a *single* stream of experience,” which must be carefully separated from “objective” time (Husserl 1913/2014, 234).

Husserl’s terminology shifts over the years, but he continually distinguishes three levels of time which correlate to his understanding of levels of experience: (1) objective time (the *object* of experience), (2) subjective time (the *experience*, *Erlebnis*), and (3) the absolute flow of subjectivity (the experiencing, *Erleben*) (Husserl 1905/1991, 77).⁹ When temporal objects such as a melody (level 1) enter our awareness, they do so as experiences or intentional “acts” such as perception, memory, or anticipation (level 2). The perceived “unity” of a melody is the result of the inner time-constitution, which synthesizes individual tones through retention of passed tones and protention of coming tones. The absolute flow (level 3), which Husserl also calls the absolute “time-constituting flow of consciousness” (1905/1991, 77), is the deepest level of “absolute subjectivity” which constitutes temporal experiences and their overall unity in our everyday lives.¹⁰ If we accept Husserl’s basic notion, it makes sense that time can be perceived as slowing down or even stopping (subjective time), even though we know that neither clock time (objective time) nor our experiencing (absolute flow) stops. The inspiration for the flow metaphor underpinning Husserl’s analysis of time is no mystery; Husserl explicitly states that “[c]onsciousness is a constant Heraclitean flux” (1905/1991, 360).¹¹ Heraclitus is widely regarded as the historical origin of the philosophy of becoming, sometimes called process philosophy, and a central premise is epitomized in his phrase *panta rhei*, “everything flows.”¹² The concepts of lived experience, flow, and becoming thus share the same pedigree.

While Baraitser develops her argument as distinct from the philosophy of becoming, Beauvoir uses it actively, which is not surprising given her roots in phenomenology. For Beauvoir, the notion of *becoming* is as central as the perceived *lack of flow*. Husserl’s time levels make it possible to express these different but coexisting experiences of time. When we perceive subjective time as going slow or stopping, we generally know that objective time does not stop and our inner consciousness of time does not freeze—if it did, we could hardly perceive time as being “slow.” What is lost if we focus only on subjective time as “experiential” is that ongoing change is always part of our experience of time. Similarly, the concept of *flow* characterizes ongoing change, but it does not have to be understood in the optimistic sense which Baraitser and others react against. Even though the term flow is commonly used to signal a smooth experience, as in “creative flow,” there is nothing inherently positive in the term as such. Instead of choosing between an ontological and an experiential version of time, the

notion of lived time involves both and provides a ground for the richness and variety found in temporal experience.

How can we analyze this lived time in relation to endo experience? I propose the concept of *endo time* to capture the lived time of endo involving all these time levels. As a form of lived time, *endo time* rests on the phenomenological insight that subjectivity is not merely acquired over objective time. Rather than just being in time, we are fundamentally temporal. As Beauvoir and Burke describe, the way we live time is constitutive of who we become. I understand *endo time* as constituted by the ways in which endo is recognized in society and as appearing in the form of certain temporal patterns that interviewees live through. I further propose that the impact of this lived time on subjectivity can be studied by approaching becoming as a process of recognition. Hegel used the concept of recognition (*Anerkennung*) to describe how our self-relation is always mediated by others. Drawing on the recognition theory of Axel Honneth, I understand recognition as signifying an intersubjective process of becoming constitutive of both subjectivity and social relations over time (Hegel 1807/2018; Honneth 1995). Honneth's theory reconfigures the concept of justice in terms of due or withheld recognition. It has a much broader scope than dealing with identity categories or identity politics and rather deals with the psychosocial and normative processes through which people maintain a practical relation to self and, simultaneously, a social standing.

Honneth describes three main modes of recognition—love or emotional support, respect, and esteem—which are required for sustaining a positive self-relation. We develop *self-confidence* by being loved and cared for; we acquire *self-respect* by being awarded rights and legal status; we gain *self-esteem* by being appreciated for our particular traits and achievements (Honneth 1995, 129). Several interviewees describe how they lost their sense of self-worth when other people repeatedly denied their illness experience. Honneth's theory suggests that this is due to the fundamental entanglement of recognition and individualization. If other people repeatedly doubt your experience of symptoms, this can eventually have a negative effect on your own self-relation. Denial of recognition has the power to injure a person's self-relation precisely because it was always acquired intersubjectively to begin with (Honneth 1995, 131).

The concept of recognition already presupposes a temporal dimension.¹³ But the temporal patterns of recognition need to be theorized as such in order to describe the lived time of endo experience. Recognition of endo does not occur once and for all when receiving a diagnosis but is rather negotiated in the everyday lifeworld through intersubjective encounters, such as those between patient and doctor, friends, family members, or colleagues. During a lifetime, we *continuously* come to exist through our interactions with others. Over time, the flow of recognition, which constitutes *endo time*, is sedimented in the lived body. Starting from the narrated lived time of interviewees, I have identified three main appearances of *endo time*: *waiting time*, *cyclical or chronic time*, and *sedimented time*. Taken together, the patterns of *endo time* harbor the insight that even if you feel like nothing happens, you also realize that unless treated the bodily processes of endo can progress and continue to flow.

Waiting time

The first temporal pattern I have identified concerns a fundamental part of lived *endo time*: the long waiting time for diagnosis and treatment and the detrimental effect this

has on the anticipation of future projects and goals. The longest waiting time for diagnosis was experienced by an interviewee whose symptoms began at *menarche* (a temporal term marking the first menstruation) at the age of 12 and who was diagnosed with endo at the age of 40. From onset of symptoms to diagnosis, 28 years passed. Another interviewee received a diagnosis 17 years after symptom onset, and at that time only by accident because of an ectopic pregnancy. Even though the severity of symptoms varies from case to case, and some have eventually found good treatment, most interviewees had repeatedly sought health care for their problems with severe menstrual pain since adolescence. Their efforts were met with doctors, gynecologists, or school nurses repeatedly telling them that “menstruation does hurt” and that “pain is normal.” As one of them describes it, when getting these responses over and over again as the years passed by, she learned that it made no sense to seek treatment because she would not receive any help.

Another interviewee who spent several years struggling to find the cause of her pain describes her experience: “Everything melted together. I had been spending that whole fall in bed.” The excerpt offers a good description of a certain temporal experience where everything in life seems to melt together because of the lack of events or progress that are usually there to organize time. When she was finally diagnosed, she had lived through 11 years with endo without knowing what was wrong. After beginning treatment, she describes starting to feel like she was able to get out again and maybe take up her studies. Only when symptoms are relieved, it becomes possible to imagine a future again. When symptoms are too severe, the present has a tendency of occupying one’s temporal horizon. Even though Beauvoir’s description of “the temporality of waiting” is clearly developed in another time and place and based on a heterosexual project, there are striking similarities in today’s endo experiences that make the notion of living “a passive present” useful. The result of living in *waiting time*, such as spending a fall in bed unable to pursue one’s will and desires, is a similar form of confinement as the one Burke finds in Beauvoir, not only to immanence but to the present (Burke 2018, 2019).

In line with previous research, interviewees describe their pain as overwhelming, intense, and sometimes so severe as to cause vomiting or even fainting (Denny 2004; Huntington and Gilmour 2005). They describe how they went through years of going in and out of the emergency room when the pain reached unbearable levels. Despite repeated visits to physicians and gynecologists they were sent home, most often with non-prescription painkillers. One interviewee told me that the emergency staff got so used to seeing her that all they did was yell: “It’s her again—morphine!” When asked if the physicians generally knew of the term “endometriosis,” another interviewee responded: “During the first years, they just said: ‘OK, I will have to look that up next time.’” These experiences entail even more than the passive present described by Burke and Beauvoir, it is a *painful present*, stretched out in time.

The lack of progress in the lives of several interviewees is mostly handled as a private matter and does not lead to increased attention regarding their health status. Their projects and goals for the future—in the form of education or career—are not treated by others as serious losses, echoing the Beauvoirian dissonance between women and linear time. One interviewee describes how the delay in diagnosis came to affect her prospects for the future: “Well, [endo affected] all my childhood and youth... The road to employment and the future doesn’t look very bright. So, it has pretty much ruined my future.” In the excerpt, the interviewee’s memories from school spark a realization about what kind of future her past enables. I agree with Alison Kafer’s argument that it

is reasonable to avoid the trap of considering chronic illness itself as lacking a sense of future (Kafer 2013). It is rather a case of interrogating unreasonable waiting time and, simultaneously, what kind of futures society *offers* for people with conditions such as endo. This means to “recognize embodiment as the condition of possibility for futurity” (Söderbäck 2019, 9).

In experiences of illness, our dependence on recognition from others is made manifest. Recognition in the form of diagnosis is usually required in order to receive proper treatment. Diagnosis can be understood as a form of recognition that turns a person into “a patient” and, as such, into a “proper subject” of institutionalized medicine. The term “patient” itself carries a temporal meaning. The Latin word *patiēns* means “suffering” or “enduring without complaint.” *Being* patient, it almost seems, is crucial for *becoming* a patient. The recognition as patient operates as a gatekeeping process; if we fail to be recognized as patients, the doorway to medical treatment and care remains closed. Without medical recognition people with endo are effectively denied patienthood—and through this, proper subjecthood and agency in terms of future projects and goals.

The waiting time experienced by interviewees should be understood in the light of an internationally well-documented “delayed diagnosis” of endo of up to ten years (Denny 2004; 2011; Ballard et al. 2006). Delay in diagnosis of endo has been identified as occurring on both an individual and medical level, as both patients and doctors normalize symptoms, and symptoms are often suppressed through hormones without being fully investigated (Ballard et al. 2006). Interviewees describe the long waiting time as being related to normalization of symptoms, lack of knowledge, and as the result of not being listened to or taken seriously (cf. Grundström et al. 2016).

The term “delay” in diagnosis denotes both a specific temporality attached to the diagnostics of endo and an expectation that things should be otherwise.¹⁴ There is a normative claim here that diagnosis *ought to* have come earlier. In recent years, diagnostic delay has been increasingly articulated as a pressing political issue. Interviewees describe participating in demonstrations and online activism to raise awareness of diagnostic delay. The 2017 Stockholm version of the yearly Worldwide EndoMarch was centred around the slogan: “8 years is not OK.”¹⁵ This slogan was used on banners, t-shirts, and as a hashtag on social media to draw attention to and protest against the long average waiting time for diagnosis in Sweden.¹⁶ For the third year in a row, the aim of the Swedish EndoMarch was to convince the state of the necessity of establishing National Guidelines for endometriosis care in order to enable earlier diagnosis and treatment.¹⁷ These initiatives can be understood as a struggle for recognition (Honneth 1995), where *waiting time* constitutes the prime target. *Endo time*, in this sense, is explicitly made into politics.

I understand the experiences of interviewees as being shaped by a gendered flow of recognition surrounding endo. Feminist research is rife with descriptions of a tendency within medicine not to take women’s pain seriously. In their overview, Hoffmann and Tarzian conclude that while the subjective nature and invisibility of pain offer difficulties for anyone, women are less likely than men to be taken as credible reporters of pain. Women’s pain is viewed as more emotional, and they are expected to put up with the pain that they experience (Hoffmann and Tarzian 2001). Additionally, in the case of endo, the misrecognition of symptoms is directly related to the idea of painful menstruation as a natural part of womanhood, which I will return to in relation to cyclical or chronic time. Studies also describe that the delay in diagnosis is greater when the main symptom is pelvic pain compared to infertility, suggesting a greater importance placed

on reproductive role rather than suffering (Dmowski et al. 1997). The association to womanhood and reproduction tends to feminize and—through the same move—normalize endo symptoms.

The result of living in waiting time is a form of inhibited intentionality similar to what Iris Marion Young (2005) famously found in relation to feminine body comportment. If Young describes feminine bodily existence as being characterized by *constricted space* (Young 2005, 33), and Beauvoir and Burke describe the experience of being confined to the present, I suggest that *endo time* is lived as a form of *constricted time*, characterized by waiting time and the experience of waiting in pain. The ultimate consequence of delayed diagnosis and confinement to the present is that of being robbed of a sense of the future—and with it, the opportunity to determine your own life course and pursue individual aims and goals. *Endo time*, lived as waiting time, means exactly this: gender does not simply pre-exist such temporal patterns; endo as phenomenon is gendered through these temporal patterns. Waiting for diagnosis and treatment is an essential part of how the misrecognition of endo appears.

Cyclical or chronic time

The second temporal pattern I have found concerns a present shaped by the temporality of symptoms. Two major themes emerge in the interviews: cyclical symptoms are *normalized*, while chronic symptoms are *stigmatized*. Both normalization and stigmatization tend to have a negative impact on opportunities for care and support from others and on one's self-relation.

An interviewee describes a common temporal pattern related to endo pain. Among her friends with endo, there are roughly two different types: “Those with pain only during menstruation” and “those with constant pain.” These two types of pain correspond to a medical understanding of different durations of pain: First, endo pain in the form of *dysmenorrhea*, that is, painful menstrual cramps of uterine origin, is related to menstruation (De Nardi and Ferrari 2011; Iacovides et al. 2015; Allaire et al. 2017). It has a cyclical structure of monthly recurring periods of pain. Secondly, endometriosis is the most frequent gynecological cause of *chronic pelvic pain* (CPP). Chronic pelvic pain is defined as noncyclical intermittent or constant pain in the lower abdomen or pelvis of at least six months in duration, not occurring exclusively with menstruation or intercourse and not associated with pregnancy (Bajaj et al. 2003; Ahangari 2014; Allaire et al. 2017). In other words, it is a pain that persists without a clear cause—a pain that has become chronic. The Greek word for time, *khronos*, is used for one of the fundamental categorizations of medicine; since antiquity, the term *chronic* has been used to describe illnesses that persist for a long time in contrast to conditions that are *acute* (Nutton 2012, 125). We often understand illness in relation to expected temporal phases such as falling ill (the onset of symptoms), being ill (stabilization), and becoming well (recovery).¹⁸ But this image of illness as something that *passes* fits badly when it comes to a chronic condition such as endo.

How do these different temporalities of endo pain appear in the lifeworld? Several interviewees describe how their endo pain first began in connection with menstruation, appearing monthly. But in many cases, after a few years, the pain became chronic and started to appear more or less on a daily basis. Their endo pain could be triggered by specific activities such as penetrative sex (*dyspareunia*) or medical examinations at the gynecologist and could persist for a long time after those events. As one of them said: “Sometimes [it lasts] an hour, sometimes a few weeks.” The chronicity of endo is thus

related both to the incurable nature of the condition and to persistent, ongoing, daily pain. The “cyclic chronicity” of menstrual pain has been noted in previous research (Przybylo and Fahs 2018). However, based on the interviews, I find it important to separate cyclical pain from chronic pain since these temporalities of pain are often recognized in different ways.

In the interviews, the pain that was temporally linked to the menstrual cycle was usually *normalized* and viewed as a natural part of “womanhood,” a notion also encountered by a non-binary interviewee. Doctors repeatedly said that “Menstruation does hurt” and that “There is nothing wrong with you.” Even though menstrual cramp is defined by its temporality as *period* pain, it is an outlier to the acute/chronic pain dichotomy, both because of its cyclical structure and its status as a non-pathological form of pain. Endo is regularly reduced to painful menses, resulting in a “normalization to the point of invisibility” (Jones 2016, 559). The misrecognition of endo pain resembles a common pattern where medically unexplained pain that does not correspond to a clear case of injured territory is often understood as being merely psychological (Kafer 2013; Melzack and Katz 2013). Ela Przybylo and Breanne Fahs describe how menstrual pain has been “denied the status of *real* pain” and has been curiously absent even from feminist work on menstruation (Przybylo and Fahs 2018, 207).

I am in agreement with Söderbäck, who argues that the relation between time and gender (women–cyclicity and men–linearity) still remains unacknowledged and needs to be deconstructed (Söderbäck 2019, 8). I suggest that the very association between women and cyclicity, already described by Beauvoir, hinders a proper recognition of the suffering of endo, as described by the interviewees. The cyclical structure of pain and its association with female embodiment tends to cover over a pathological state. This normalization of endo, tied to cyclicity, risks orienting patients towards endurance and concealment, rather than patienthood and treatment.

Interviewees describe that even when the existence of pain was not questioned as such, their *reaction* to pain often was. If the pain you experience as severe is deemed by others as normal, it is easy to get the sense that your complaints must be due to imagination or exaggeration. The experience of perceiving symptoms that are normalized and not validated by others led several interviewees to form an image of themselves as being “weaker” than others or “lazy.” They felt ashamed of being so troubled by their symptoms and for failing to control them. Why did everybody else seem to manage menstrual pain so much better than they did? The repeated experiences of not being taken seriously by doctors led one interviewee to periods of depression and to constantly question herself and her own abilities. It got to the point where she was thinking: “I must be crazy. There is something about me that makes me unfit to handle things like other people.” In contrast, finally being recognized through the frame of diagnosis, was in several cases deemed important for their self-relation: “For me, getting [the diagnosis] in writing has been incredibly important for my self-esteem, so you won’t have to doubt yourself.”

If the pain related to menstruation and cyclicity was often *normalized*, chronic or unpredictable pain was often unintelligible for others and, as such, *stigmatized*. During adolescence, the existence of chronic endo pain was generally not known by interviewees or by people in their surroundings, and perhaps most troubling, neither by the doctors they encountered. One interviewee describes how it is also “scarier” to tell people about conditions that are chronic:

Because you know that people have some patience, but it's very limited. If you have hurt yourself or you have a temporary condition (...) you heal when you get your medication. It is something completely different when you know that this problem will go on forever. According to my experience, people only think of you as being difficult or whining if you describe how you feel, when you're not hunky-dory.

In the quote, the interviewee describes how “people think of you as being difficult or whining” and links this experience specifically to having pain that does not go away. Chronic endo pain risks being seen as an undesirable character trait, a fact that can lead to self-silencing (Cole et al. 2021). The quote also illustrates how chronicity *itself* presents difficulties in relation to other's responses to pain. This phenomenon can be understood as encountering certain frames of recognition (Butler 2009), which shape how different temporalities of pain are perceived. These frames are related to gender, as the normalization of cyclical pain illustrates. They are also related to what Robert McRuer (2006) calls compulsory able-bodiedness, a cultural understanding that frames disability in terms of lack or imperfection. Similar to other chronic illnesses, endo can be a major cause of disability (Wendell 2001; Jones 2016).

Symptoms have different temporalities, and symptoms also affect how we can perform temporally. In my very first interview, the concrete temporality of endo pain came up when I asked about when pain occurs:

It just appears. I can have it in the morning or I can wake up and not feel pain at all and then it just appears, boom! I don't have to do anything special... When I walk I can be in pain, when I sit I can be in pain, when I prepare food I can be in pain, when doing the laundry I can be in pain. I can be in pain at any time.

Endo pain is here described as a fundamental part of everyday life, but the pain is also described as *an event*, happening unexpectedly (cf. Dastur 2000; Oksala 2004). The “event of pain” does not comply with planned schedules. Pain is often described in the interviews as getting in the way of your plans and social activities, forcing you to make cancellations at the last minute—which tends to render you socially “difficult.” Endo clearly disrupts the powerful desire to maintain “[t]he self-possession and control that the modernist ideal of embodiment demands” (Shildrick 2009, 22). For the individual, acute pain may be experienced as being out of the ordinary, but it usually does not affect your self-relation or identity in any major way. Chronic pain, on the other hand, has the tendency to render you different, or “crip”; it is an Othering experience.

The fields of crip theory and queer theory have both highlighted the ways in which temporality plays an important role in the construction of normality and socially meaningful subjects (Halberstam 2005; Freeman 2010). Elizabeth Freeman uses the concept of *chrononormativity* to describe “the use of time to organize individual human bodies toward maximum productivity” (Freeman 2010, 3). Similarly, Alison Kafer uses the concept of *crip time* to address the role of temporality in the construction of able-bodiedness (Kafer 2013).

For several interviewees, endo had an impact on education, not only because of absence but also because pain affected their ability to concentrate: “Some days are fine but other days I don't have a clue about what [the teacher] is talking about. But presence is mandatory, so all I can do is sit there and suffer.” Educational settings tend to be run under strict time constraints which involve everything from demands

to arrive *on time*, absorb information at a certain *speed*, and perform *spontaneously* at any given moment (Price 2011, 62). When asked how endo affected education, an interviewee replied: “Well, it took me seven years to finish high school.”¹⁹ Two interviewees were not able to graduate from high school due to their health, exemplifying how childhood disability can have a negative effect on social mobility (Chatzitheochari et al., 2022).

A failure to conform to chrononormativity is bound up with the risk of what could be called *temporal* stigma. Erving Goffman defined stigma as an attribute that “constitutes a special discrepancy between virtual and actual social identity” and which classifies the individual as being of a less desirable kind (Goffman 1963, 3). Stigma is often associated with visual marks, but the aspect that threatens to mark the interviewees as different is their deviation from temporal norms. Just like other sets of norms, chrononormativity can make you “incongruous with our stereotype of what a given type of individual should be” (Goffman 1963, 3). The invisibility of a chronic illness such as endo presents an opportunity to avoid stigma by not disclosing your condition, for example, in relation to potential employers. As one interviewee describes it:

I want to pursue an academic career, and I am afraid of telling someone, who might become my future employer that I have so many issues. I have worked here as a research assistant, and I would like them to offer me a position again. It might not be a good thing if they know that I experience the level of difficulties that I do.

Several interviewees describe how they felt they had to work despite severe pain in order to avoid stigma: “You learn to bite the bullet. Half the day, you do nothing, and the other half you have to be *twice* as productive so that no one will notice.” Time has to be bent when your condition makes it impossible to fit in according to chrononormative *paces* of work. Another option is to tamper with the body itself: some interviewees used contraceptive pills to plan *when* menstruation occurs. They would “schedule” their menstruation to weekends to keep it from interfering with work. They also learned to take painkillers *in time* so that their pain would not reach unmanageable levels. Acts like these are all part of an everyday time management, that is needed to keep it “under control.” Even though most people engage in some kind of management of body and self, and modern medicine offers many tools to do so,²⁰ a chronic illness can make it much more difficult to adhere to temporal norms. Regulation of time was often an aspect that made it difficult to work or keep a job altogether. In turn, temporal flexibility or the opportunity to work part-time was a factor that enabled work (cf. Wendell 1996, 20).

Some interviewees describe how endo has “ruined” their career or forced them to take jobs below their level of competence. They also described how these difficulties in adhering to work life demands had a negative impact on their self-relation. One interviewee describes how she even became suicidal because she felt “like a total failure”: “I am almost 30 and haven’t achieved anything in life. I have nothing that I can show ... like ‘I have achieved this’ or ‘I am good at this.’” When asked why she felt this way, she describes that “it is because of how I have been treated by others, and the responses you get.” Another interviewee describes how these negative thoughts got “stuck in her head” and also made her doubt that she could ever manage to take up her studies again, which was her dream. This kind of negative self-image and periods of depression are very common in the interviews and feelings of self-doubt are often linked to experiences

of encountering disbelief and denial of symptoms. As Honneth argues, our sense of self-esteem is dependent on being recognized as a unique individual who has something valuable and productive to offer society (Honneth 1995; Fraser and Honneth 2003). Since Sweden is a country firmly based on a dual-breadwinner model, all individuals are expected to work to make a living irrespective of gender, and social entitlements are based on individual labor market participation (Lewis 1992). If you fail to be recognized as a productive citizen, it can be difficult to uphold a sense of self-esteem, which is often expressed in the interviews.

The frames of recognition related to different temporalities of pain present a double-edged dilemma: cyclical pain is regarded as *too normal* to be understood as pathological, while chronic pain is *too abnormal* to be intelligible at all in relation to chrononormative lifecourses.

Sedimented time

The final pattern I have identified concerns the relation between passed time and the body's concrete materiality, understood from two different angles. First, through the relation between heavy menstrual flow, cultural rhythms, and embodied habits. Second, through sedimentation of the flows of menstruation, recognition, and time.

The phenomenological concept of sedimentation goes back to Husserl, and both Beauvoir and Maurice Merleau-Ponty make use of the notion to discuss how repeated acts, goals, values, and gender stereotypes are sedimented into the lived body (Beauvoir 1949/1988; Merleau-Ponty 1945/2012). The lived body is an intertwining of subject and object—"from one side a thing among things and otherwise what sees them and touches them" (Merleau-Ponty 1968, 137)—and our way of living time is embodied in a myriad of ways. Drew Leder describes how a stressful relationship or job situation might lead to a clenched fist or a sore neck and even to a constriction of the arteries. When we hurry and struggle to compress time, visceral functions such as breathing and heartbeat become compressed and accelerated too. When we are bored by a slow conversation, we might tap our foot or clench the chair—actions that, in turn, might lead to a clenching of blood vessels. The body does not simply react to prior mental intentions; it *engages* in them in an ongoing "symphony of virtual action" (Leder 1998, 28).

We perceive temporal patterns in the embodied habits of others, which we can be *in or out of sync* with. Habits have a double nature: they are traits of individuals, but at the same time social. They are derived from "cultural rhythms" and founded in collective actions. They arise through repetition of everyday activities and social routines—and eventually become characteristics of who we are (Charmaz 2002). Among such cultural rhythms, some are mundane indeed: for example, the *frequency* of bathroom visits. While being one of the most private situations of all, in certain settings, such frequencies become a public affair. As an interviewee describes, during school, she did not want to go to the bathroom *too often* to manage her menstrual flow:

I couldn't go from class every other hour. I cared so much about school and like ... no one in class went out so often. No one was bleeding like I was. So [the tampons] stayed in much longer. And I had heard horror stories about someone who had a tampon in for too long and had to amputate her leg! So, I was constantly having this fear of falling ill, but I wouldn't dare change too often out of fear of being judged or that someone would discover what I was doing.

The problem of *menorrhagia*, or heavy bleeding, is a common theme in the interviews and concerns a management of both time and identity. In the quote above, the fear of being judged as different is mixed with a fear of not responding to the bodily processes of menstrual flow in time. The feeling of difference is related to another version of chrononormativity: cultural rhythms regarding the “normal” frequency of bathroom visits. In breaking the rhythm, she would break a temporal norm and risk temporal stigma. Which temporality should she respond to, the cultural rhythm or the temporality of the body?

The experience of heavy flow is a major cause of anxiety, and situations like these are common in the interviews. When growing up, many were not aware of the fact that heavy bleeding could be a sign of pathology, it was just treated as something they had to deal with themselves. Interviewees describe that this understanding was many times repeated by doctors if they eventually did seek medical care. After six months of heavy bleeding and painful periods, the interviewee quoted above finally decided that something must be wrong and her mother took her to see a gynecologist. It was a male gynecologist telling her that: “It is common to experience pain. Menstruation does hurt. There is nothing dangerous with heavy bleeding.” Her experience of heavy bleeding as pathological was simply dismissed.

Management of heavy flow is a complex phenomenon involving several sets of gendered norms. In addition to rhythms in general, it is related to menstrual stigma and concealment (Douglas 2002; Seear 2009; Johnston-Robledo and Chrisler 2013) and to the devaluation of female bodies traditionally understood as “leaky” and as lacking secure boundaries (Grosz 1994; Shildrick 1997). Some have noted how menstrual stigma has the peculiar feature of both reflecting and contributing to women’s lower social status (Beauvoir 1949/1988; Johnston-Robledo and Chrisler 2013). A central premise of Honneth’s recognition theory is that only subjects who learn to “appear in public without shame” are truly sustained to flourish socially (Honneth 2004, 355). Like shame in general, menstrual stigma is more than an individual psychological state—it is a gendered cultural practice (cf. Ahmed 2004, 9).

While all menstruators tend to menstrual flow, the situations described by interviewees consist of managing the symptoms of an illness even though it is not always recognized as such. The fear of visible blood stains led some interviewees to use “double protection” in the form of tampons and pads, in order to stay “safe.” Art historian Jenni Sorkin argues that stains elicit shame because of their tendency to mark the wearers themselves as being dirty, messy, or poor. Stains also have a temporal dimension: they mark the event of a bodily transgression and thus the passage of time by leaving a *trace*—tainting the *now* with the *then* (Sorkin 2000). Interviewees describe how the management of heavy flow is learned early on, often accompanied by strategies that involve avoiding “risky” situations altogether, such as sleepovers at friends or school gymnastics. This, too, threatens to mark them off as different in relation to peers. Once again, the interviewees’ situation presents a dilemma: in their effort to avoid staining, they are liable to another stigma by breaking collective habits. Both stains and broken habits mark forms of disorder. If dirt is classically defined as matter “out of place” (Douglas 2002), a broken habit can be understood as action “out of time.” It is often precisely at the moment of transgression that the existence of norms becomes clear. This does not mean that interviewees become conscious of temporal norms as such, but they express perceiving themselves as being norm-breakers in the negative sense of inducing shame and stigma.

In addition to cultural rhythms and embodied habits, how is *endo time* sedimented if we take the concrete materiality of the body into account? The phenomenological term sedimentation is especially fitting in relation to the materiality of endo. In general, the term sedimentation refers to the process where matter sinks and settles at the bottom of rivers or other bodies of water. Menstrual flow, on the other hand, is the process where the body sheds the lining of the uterus (the endometrium) along with blood once a month. The “Sampson Theory,” which has dominated the medical understanding of endometriosis since it was first put forward in 1927, holds that blood containing endometrial tissue flows back into the body as “retrograde menstruation.” Even though the pathogenesis of endo is still unclear, and retrograde menstruation is a wider phenomenon, the defining feature is endometrial tissue settled outside of the uterus. This ectopic tissue responds to the cyclical changes of estrogen and grows and bleeds with each menstrual cycle—causing lesions, scar tissue, inflammation, and pain (Kitawaki et al. 2002; Seear 2014, 9–10; Burney and Giudice 2019). Hormone therapy to suppress the process of menstrual flow is, therefore, a first-choice treatment, aside from painkillers or surgery.

Because endometrial lesions can continue to build up and grow and spread to other organs, time to diagnosis is vital. Delay in diagnosis increases the risk of developing both chronic pain and infertility (Socialstyrelsen 2018, 13). The time spent waiting for diagnosis and waiting to be taken seriously means time for the tissue to grow. Several interviewees express believing that their condition may have gotten worse because of the long waiting time for diagnosis and treatment. As one interviewee describes:

They noticed that it had gone so far, it had even reached the abdomen. When you go untreated, I mean for a really-really long time, it can grow into the abdomen and into other organs, it can grow into your intestines and everywhere ... And this is because you have not been able to get help. You might not know what endometriosis is. You just walk around with this unexplained pain ... Or, you do know what endometriosis is, but you try to find doctors that will take you seriously, but they don't. In the end, it can go this far that the endometriosis has grown like it did in me.

Another interviewee has a similar reaction: “I will be in pain every day for the rest of my life because I was not helped in time.” Interviewees describe the lack of recognition of symptoms over time as a causal factor behind an aggravated condition. The experience of interviewees corresponds to the temporality of chronic pain, which does not simply imply a temporal extension of acute pain but involves distinct mechanisms. Due to the body's functional and structural plasticity, chronic pain involves remodeling and reorganization of synapses, cells, and circuits (Kuner and Flor 2016). Chronic endo pain is increasingly understood as the manifestation of central sensitization, a complex phenomenon where nerves become wound-up and exaggerate pain responses (Bajaj et al. 2003; Allaire et al. 2017)—like a memory of pain that gets stuck on repeat. Because of this effect, the danger of applying a “conservative wait-it-out approach” has been observed more generally in relation to chronic pain (cf. Heshusius 2009, 99–100). When acute pain is not recognized and treated in time, as several interviewees express, it runs the risk of becoming chronic. Becoming chronic is thus a process of habituation and sedimentation involving recognition, processes of the body, and the flow of time.

Of all forms of personal degradation, Honneth identifies violations of physical integrity as representing the most harmful because these acts carry with them the potential to have the most destructive impact on a person's self-confidence (Honneth 1995, 132–33). What makes experiences of physical injury so special, according to Honneth, is “not the purely physical pain but rather the combination of this pain with the feeling of being defencelessly at the mercy of another subject” with the ultimate consequence of losing trust in both oneself and the world (Honneth 1995, 132). Even though endo pain is not intentionally brought upon the sufferer, the lack of recognition and treatment can be experienced as being deprived of the opportunity to freely control one's own body. The doctor–patient relationship is, by its nature, asymmetrical in terms of power but it requires a certain level of mutual recognition to function well. When doctors dismiss their patients, this involves the risk that the patients, correspondingly and over time, lose trust in them. The loss of trust experienced by interviewees illustrates the fragility of relations of recognition and, simultaneously, the kind of perceived injustice that can motivate calls for change on both an individual and collective level.

Unsurprisingly, several interviewees describe losing trust in doctors or the healthcare system more generally. Medical research has emphasized the profound importance of trust for effective medical encounters, including patients' willingness to seek care, reveal sensitive information, and adhere to treatments (Hall et al. 2001; Smith 2017). Trust is regarded as a core, defining characteristic of a meaningful doctor–patient relationship, in the same way that love or friendship defines the quality of primary relations. Trust can be defined as an affective attitude with both a history and an outlook, a “forward-looking evaluation of an ongoing relationship” (Hall et al. 2001, 616). When patients experience betrayal in medical relationships, such as feeling that their physician has acted counter to their best interest or taken advantage of their vulnerability, their reactions have been described as closer to moral outrage and indignation than mere disappointment in results (Smith 2017). Such moral outrage or indignation is precisely what Honneth (1995) regards as the “moral grammar” of social conflict and as the “engine” behind struggles for recognition.

Concluding remarks

Through the concept of *endo time*, I have explored how gender works as a specific orchestration of time in relation to endo. *Endo time* can be thought of as a pace or a melody that the body comes to animate. Living in *endo time* is perceived by interviewees as a form of gendered injustice, and they describe both strategies for coping in everyday life and mobilizing for change, such as demanding National Guidelines for better and earlier recognition, diagnosis, and treatment. I read such initiatives as protesting what amounts to a waste of time and potential—a waste of their own finite lifetime.

I have described three temporal patterns which illustrate how *endo time* appears. I have described how *waiting time* is lived as a form of constricted time, characterized by the experience of waiting in pain and ultimately being robbed of a sense of the future and the opportunity to pursue individual life projects and goals. I have described a present shaped by the temporality of symptoms in the form of *cyclical or chronic time*. When symptoms are cyclical, they are often normalized as a natural part of womanhood. A failure to cope is related to feeling “crazy” or “weak”. When symptoms are chronic, they are more often stigmatized. A failure to conform to chrononormative

ideals of productivity is related to feeling “like a total failure” and to a loss of self-esteem. Finally, I have described how endo time is lived as *sedimented time* in relation to the concrete materiality of the body. The problem of heavy bleeding involves a management of both time and identity in order to avoid temporal stigma. Interviewees face dilemmas where the temporality of bodily processes clashes with cultural rhythms of normalcy. The time spent waiting for diagnosis means time for endometrial tissue to grow, increasing the risk of developing chronic pain and infertility. The experience of being dismissed by doctors is also sedimented in the form of a loss of trust in doctors and the healthcare system.

Through the concept of *endo time*, I have picked up the call from Jones to “politicize endo pain”. I have added to this endeavor by specifically addressing how experiences of endo and processes of recognition can be conceptualized in temporal terms. The *endo time* inhabited by interviewees is the result of social recognition entangled with processes of the body, such as menstrual flow. There is nothing merely biological about these experiences, and it cannot be understood as merely social. The way tissue grows, the way the body bleeds, and the way pain appears will all be qualities of the recognized body. I am in full agreement with Jones’ conclusion that those with endo need social recognition and legitimization, in addition to support and access to healthcare: “It is about how we spend, divide, and use resources, *including time*” (Jones 2016, 566, emphasis added). Even though all pains and illnesses will have their own cases of troubled waters, the concept of endo time might strike a chord for other lived realities as well.

I have argued for a phenomenological understanding of lived time, which does not insert a separation between becoming and lived experience. Such an understanding gets rid of the assumption that “flow” and “becoming” implies optimism. This is important because it makes it possible to describe the negative consequences of inaction in the face of an ongoing, progressing 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. Endo time is meant to capture the complexity involved in experiences of time—and the ways in which different levels of time are coexisting and interrelated. Waiting would not be experienced as waiting if we did not simultaneously experience time as something that does not pause while we wait.

As Husserl explains, there are technical difficulties involved in describing the flow of time:

[A]n experience (Erlebnis) is not, and never is, perceived in its completeness, it cannot be grasped adequately in its full unity. It is essentially something that flows, and starting from the present moment we can swim after it, our gaze reflectively turned towards it, whilst the stretches we leave in our wake are lost to our perception. (Husserl 1913/2014, 139)

Consciously turning our gaze towards time and trying to grasp the temporal involves an operation that risks transforming it into a foreign state, of solidifying that which flows. Perhaps it is only in retrospect that we can hope to describe the workings of time. While being aware of these difficulties, the concept of *endo time* offers a way to extract prominent temporal patterns from the stream of endo experience as described by the interviewees. 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 understand them as *lived*, as sedimented, and as constitutive of who and what we become.

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Notes

1 My use of the term *endo* instead of *endometriosis* is part of an endeavor to treat this condition as *more* than a medical fact and instead as a phenomenon that appears in the lifeworld of interviewees. In using the term “endo,” I also attend to the language used by many people with endo themselves as well as activist organizations, self-help groups, cultural critics, and academics. 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).

2 I am quoting the government of Sweden at the time of the interviews (Regeringskansliet 2015).

3 The semi-structured, in-depth interviews were all conducted by the author in 2018.

4 The identification of endometriosis is commonly attributed to Carl Rokitansky in 1860s Vienna, but due to discussions regarding the definition of the “essence” of endometriosis, this has been debated, and a dissertation by Daniel Christianus Schrön presented at the University of Jena in 1690 is now sometimes cited as the first description of endometriosis. For a longer discussion, see Giudice et al. (2012, 3ff.).

5 See, e.g., Beauvoir (1949/1988), Felski (2002, 2000), and Kristeva (1995).

6 As Burke notes, even texts focusing specifically on the topic, such as the anthology *Time in feminist phenomenology* (Fielding et al. 2011), “do not consider Beauvoir as part of the classical or feminist phenomenological considerations of temporality” (Burke 2018, 112).

7 In connecting *endo time* with the notion of gender as lived time, I am mainly referring to how endo is generally recognized as a “women’s disease” and “coded feminine” (Jones 2016, 558). That does not mean that endo only affects women; endo affects transmen, one of my interviewees is non-binary, and in rare cases, endo has been found in cis-men (Rei et al. 2018). *Endo time* is meant to capture how endo as *phenomenon* is recognized and feminized—at times, irrespective of the individual’s gender identity. I make use of gender-neutral terms such as *menstruator* when this is most accurate, but also terms such as *women* to mark how endo is feminized or when referring to the term used in previous research.

8 Husserl’s writing on time spans three decades and several volumes, comprising more than a thousand pages devoted to the topic. Even though Husserl’s terminology shifts over the years, basic ideas prevail, such as his idea of three levels of constitution involved in time-consciousness, and particularly “the absolute time-constituting flow of consciousness” at the deepest level (Brough 2010, 22).

9 A few years later, in Hua XXIII of 1911–12, the levels are expressed with different wording and in reverse order: the absolute time-constituting flow of consciousness refers to “the *experiencing*”, subjective time to “the *experience*”, and objective time to “the intentional *object* of the experience” (Brough 2010, 23).

10 These levels should not be regarded as mere abstractions. As Husserl explains, we have an awareness of them as part of our lived experience. In fact, we have a double awareness of the absolute flow, which means that our attention can be directed either at phases of the flow (*Querintentionalität*) or at the flow itself as flowing (*Längsintentionalität*) (Husserl 1905/1991, 84–85).

11 The flow metaphor is not used exclusively in relation to the deepest level of subjectivity. In the C-manuscripts, Hua XXXIV of 1930, Husserl refers to three “senses of flowing” and to objective time as “the world-time in which everything real ‘flows’—the flow of time, becoming, etc” (Husserl quoted in Brough 2010, 24–25).

12 See Seibt's entry on "Process philosophy" in *Stanford Encyclopedia of Philosophy*. Viewing the history of philosophy from this perspective means that thinkers such as Heraclitus, Hegel, Heidegger, Bergson, Nietzsche, Deleuze, and pragmatists such as George Herbert Mead—who are often understood as belonging to different schools of thought—are part of a strain specifically addressing processes of becoming and change (Seibt 2012). Honneth's recognition theory takes inspiration from Hegel and Mead who are both part of this strain.

13 Honneth describes how Hegel came to adopt a processual understanding of Spirit as characterized by the "permanent repetition" of "externalization and return" (Honneth 1995, 31). Similar to the phenomenological account above, Hegel does not understand time as externality. In *Encyclopaedia of the philosophical sciences*, he writes: "everything does not appear and pass in time; time itself is this *becoming*, arising and passing away" (Hegel 1817/2015, 230). He makes an explicit reference to Heraclitus when stating that *all flows* and *all is a becoming*. When Beauvoir uses the notion of becoming, it is based on this philosophical provenience. For an overview of Hegel's influence on Beauvoir, see Hutchings (2003, 2017).

14 Delayed diagnosis is generally defined as "Non-optimal interval of time between onset of symptoms, identification, and initiation of treatment" (NLM 2010).

15 In Swedish: "8 år är inte OK."

16 Globally, the time to diagnosis is estimated to five to be ten years. In the US, the time to diagnosis has gone from 12 years in 1995, 9 years in 1998, to 4.4 years in 2017 (Soliman et al. 2017). A recent study in Sweden shows that the average time to diagnosis is now five to seven years (SBU 2018).

17 In Sweden, the central government establishes national principles and guidelines in order to assure largely tax-funded equal access to good-quality healthcare services for the entire population (Swedish Institute 2015). While the guidelines provided by the National Board of Health and Welfare do not uphold a legal status, they are meant to support decision-makers such as politicians and agency chief executives, helping them to allocate resources in accordance with the needs of the population so as to maximize possible benefit.

18 It has been argued that by identifying different temporal phases of illness, it is possible to enhance the ability of intensive care units to provide the most appropriate therapies that facilitate a patient's recovery. This framework is called using a "phases-of-illness paradigm" to align patients with specific goals and treatments (Pamplin et al. 2011).

19 In Sweden, "Gymnasiet" normally consists of three years.

20 Compare how Foucault's notion of governmentality has been used by several scholars to make sense of the tension between self-discipline and empowerment that modern medicine and technology make possible (Petraiki et al. 2018). See also Armstrong (2014) for a historical account of patients and agency, and Chiappori and Orefice (2008) on birth control and female empowerment.

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