

## Endometriosis stories

### *'Thick' temporalities in frontline screening in Belgium*

Collectif Endo plurielle

#### Introduction

Endometriosis is a complex medical condition that remained largely unrecognised for years but which has recently gained visibility as a significant public health issue.<sup>1</sup> Characterised by the growth of tissue similar to the endometrium outside the uterus, it causes inflammatory reactions and physiological lesions (Guidone 2020). Symptoms vary widely among individuals and fluctuate with hormonal cycles, often manifesting as chronic pelvic pain. Affecting approximately 10 per cent of the adult female population, endometriosis increasingly is referred to as a 'modern epidemic' (Seear 2014), even though it still takes an average of seven years for its lesions to be diagnosed (Nnoaham et al. 2011). This prolonged diagnostic process delays medical response and follow-up care, leading to serious repercussions for those affected, who may struggle in their social, professional, sexual and family lives (Culley et al. 2013). The condition has often been overlooked for various gendered reasons, including the denial and normalisation of menstrual pain (Seear 2009; Grundström et al. 2018), the challenges in communicating and acknowledging such pain (Bullo 2020; Helosvuori and Oikkonen 2024), and a general lack of understanding of women's bodies and menstrual cycles (Guidone 2020; Coville 2023). This 'epistemology of ignorance' (Tuana 2006) has hampered the emergence of a meaningful public debate on endometriosis, even while advocacy groups in many Western countries are now pushing for greater awareness of this condition (Hudson 2022). This is certainly the case in Belgium, where public attention to

endometriosis has led to the development of local activist and healthcare initiatives dedicated to a better medical management of the condition. Since September 2022, our research collective has been involved in a research action on primary care for endometriosis. We were able to follow the implementation of a decentralised frontline screening protocol for endometriosis in a family planning clinic in Belgium. This initiative aims to reduce the therapeutic delay while reaching a socially diverse population in primary care settings. Our research is based on a collaboration between two health professionals working in the family planning clinic and a group of social scientists from the University of Liège.

In this chapter, we intend to discuss issues relating to the production of temporalities, the material configuration of care and the organisation of power relations (Sanz 2017; Greco and Graber 2022) in the Belgian context of primary care for endometriosis, which is described in the next section. Biomedicine structures temporality through skilful coordination of bodily activities via tools, protocols and treatment plans (Mol 2002). Temporal regimes unique to biomedicine – such as ‘chronicity’ (Greco and Graber 2022), liminality (Honkasalo 2001) or ‘potentiality’ (Taussig, Hoeyer and Helmreich 2013) – influence our perception of the body, self and health. Biomedicine is infused with cultural notions such as hope and progress, which in turn shape patients’ attitudes toward the future (del Vecchio Good et al. 1990). Biomedicine, however, is not immune to the social stratifications it participates in reproducing (Berg and Mol 1998). Social factors such as class, race, gender and ability can hinder access to ‘timely’ treatment. This can result in a *therapeutic disjuncture* (Sanz 2017), where there is a harmful gap between the delay in receiving care and the anticipated trajectory of recovery. Therapeutic disjuncture is also relevant to endometriosis, as bodies become ‘sites of discordance’ between the demands of the healthcare system and the lived experience of chronic pain (Whelan 2007; Denny 2009). The relationship between physiological lesions and the intensity, duration and quality of pain is not always straightforward. Therefore, the temporal scales in which endometriosis is experienced often fall outside the scope of medical practices aimed at assessing, measuring and identifying pain (Helosvuori and Oikonen 2024). These practices often fail to account for the social realities in which women must make sense of their pain as well as their own perceptions of time. The philosopher Ina Hallström describes three temporal patterns enmeshed in the experience of living with endometriosis: ‘waiting time’, ‘cyclical time’ and ‘sedimented time’ (2024). The latter refers to the materiality of endometriosis and how it clashes with the ‘cultural rhythms of normalcy’ (Hallström 2024: 438),

much like sediments that trouble the regular course of events. These temporal regimes affect processes of recognition and trust in the medical system. To build upon this body of work, this chapter advocates for a ‘thick temporality’ in the primary care for endometriosis, drawing on Donna Haraway’s notion of ‘thick time’ in *Staying with the Trouble* (2016: 2): a time that encapsulates legacies of past situations, including the haunting dimensions of pain when striving for medical recognition of one’s lived experience; it is also a time filled with ongoing pain and its associated problems in daily life. Lastly, it is a time leaning towards different views of the future, vacillating between fearful anticipation of menstrual periods and mixed hopes and expectations with respect to one’s medical situation. This ‘thick’ temporality enables us to see how past, present and future are intricately intertwined in the experience of caring for endometriosis. This chapter highlights the contrast between the therapeutic disjuncture to which individuals with endometriosis are subjected and the thick temporality that develops in the primary care settings on which our fieldwork is based.

We outline three characteristics of this thick temporality, each corresponding to one of three empirical sections in this chapter. The first section examines anamnesis, or the attentive consideration of the patient’s history. The thick temporality of the endometriosis consultation enables the unfolding and acknowledgement of multiple unheard stories and wounded pasts. This reveals how the therapeutic delay experienced by many women continues to impact their present lives. The second section focuses on the moment of diagnosis within the endometriosis consultation. While the biomedical framework relies on pathophysiological signs as distinct indicators of a condition, we show how the family planning clinic complements this with another approach: listening to the patient’s expression of pain to guide treatment. The third section addresses the suggestion of treatment options and demonstrates how being attuned to the social injustices faced by patients opens up the possibility for new potential futures.

Our central argument is twofold. First, the ‘thick time’ of the endometriosis consultation at the clinic involves an effort to rearticulate and realign temporalities that have been fragmented in the patients’ lives. In other words, the consultation enables the past, present and future of living with endometriosis to be ‘resynchronised’ (Sanz 2017). Second, we argue that the primary cause of **this disjuncture** is the gendered epistemic injustice that women experience in the form of therapeutic delays, misdiagnoses and treatment errors (Coville 2023: 74). Epistemic injustice refers to the lack of collective resources and accessible knowledge systems

replace by « the therapeutic disjuncture » (otherwise it is unclear what the « this » refers to)

that allow individuals to be recognised as specific subjects and claim the right to appropriate care (Fricker 2007). Since endometriosis is a ‘phenomenon characterised by a lack of scientific knowledge and consensus’ (Hudson 2022: 24), maintaining a climate of ‘uncertainty’ around the condition perennially affects women’s lives. By carefully examining the stories and interactions that unfold in the family planning clinic, we demonstrate that the ‘chronic neglect’ faced by women in their therapeutic journeys and the thick temporality of frontline screening are two sides of the same coin: both depend on the value – or lack thereof – attributed to lived experience in the medical treatment of chronic pain.

## Context, methodology and positionality

In Belgium, the care structure for individuals with endometriosis is not thoroughly organised. Although some multidisciplinary endometriosis clinics have been established in expert hospital settings, patients continue to face numerous challenges in obtaining a diagnosis and receiving treatment, such as long waits, poor coordination among specialists and a lack of expertise (Roos et al. 2024). Recently, Belgian policy-makers have begun to address the issue of endometriosis, responding to calls from patient associations. Government initiatives have led to resolutions aimed at increasing awareness, promoting research and enhancing primary care for endometriosis, as well as funding local initiatives. One notable project involves a frontline unit dedicated to chronic pelvic pain, uniquely situated within a family planning clinic in Liège (*Infor-Femmes*), where we conducted our research. Talking about endometriosis at a family planning clinic is far from apolitical. This setting is more than just the framework of our inquiry; it also encapsulates the very Belgian specificities in which our study is steeped. The creation of family planning clinics in French-speaking Belgium in the 1970s coincided with the growing public debate around reproductive and sexual rights and the fight to liberalise contraception and decriminalise voluntary termination of pregnancy (Pavard 2012). In Belgium, 80 per cent of abortions (under 12 weeks of pregnancy) are performed in such clinics. Although *Infor-Femmes* does not perform abortions, it is dedicated to promoting sexual and reproductive health in other ways. *Infor-Femmes* offers social, legal, medical, psychological and sexological assistance to individuals in need. As a preventive mission for young people, it also provides comprehensive sexuality education in schools. Since 2022, *Infor-Femmes* has hosted a specific medical consultation dedicated to

endometriosis and chronic pelvic pain, which forms a unique setup in Belgium and around the world.

Unlike most common medical follow-ups for chronic pelvic pain, which usually rely on expert specialists in hospital settings, the family planning clinic works horizontally with a multidisciplinary approach. This includes various social workers, health professionals and psychologists. The *Infor-Femmes* staff is composed exclusively of women in order to provide a safe and reliable place where women feel enabled to share their difficulties. The chronic pelvic pain unit is specifically composed of sexologist Lucie Destin e and Dr Linda Tebache, an independent gynaecological surgeon specialised in endometriosis, who initiated this pilot project. A team of social scientists joined the pilot project from the very early stages onwards in order to document and support it. This assemblage creates an experimental reflective space for daily care practices, ‘where it is possible to act in new ways’ for practitioners and social scientists alike (Mol 2008: 87). As social scientists, our engagement qualifies as action research in the sense that we are a voluntary collective who intend to work together with caretakers, refusing a top-down approach (Younes 2019). We share common matters of concern among social scientists and health professionals: the conviction that frontline care is an adequate locus to reduce therapeutic delay and to address the multifaceted and social nature of endometriosis as a lived condition. In that sense we do not seek neutrality. Instead, our study has a dual purpose – transforming reality and producing knowledge about these transformations (Allard-Poesi and Perret 2003).

Our research methodology is based on the act of *listening*. In practical terms, our method was developed as follows: with the patient’s written consent, Dr Tebache recorded a series of consultations for pelvic pain. After anonymising the recordings, Dr Tebache transferred them to the research group. This method was primarily a pragmatic choice. Recording consultations enabled us to meet ethical concerns – such as an unwillingness to ‘disturb’ the course and the intimacy of the medical consultation – and external constraints, such as an inability for all of us to conduct fieldwork in person. In total, 28 consultations were transcribed and analysed collectively by the research team, with feedback from the healthcare professionals. The consultations involved women from 14 to 45 years of age and lasted from 20 to 60 minutes, with an average of 40 minutes. The analysis was then based on a cross-comparison between emerging themes and patterns constitutive of this specific type of medical encounter. We built a common analytical canvas to formalise our approach. Along the way, our choice to listen rather than to observe or to

interview turned into an innovative research opportunity. This method allowed a common and plural listening of each recording – several researchers listening to and transcribing the same consultation. This, with the generative inputs from the health professionals, enabled us to proceed to an analysis that was genuinely collective. In this contribution, we present a few selected excerpts from these recorded consultations (we use pseudonyms).

## Catching up with the wandering: the anamnesis

This section first situates the space-time of the endometriosis consultation within the social setting of the family planning clinic. We then focus on the anamnesis, that is, the first part of the consultation, dedicated to the patient's history. We aim to show how the patients' difficult therapeutic journeys find meaning in the endometriosis consultation. The *Infor-Femmes* family planning clinic is located in Liège, in the Saint-Léonard neighbourhood, a working-class district itself rooted in the city's mining history and therefore in the history of its immigration. Family planning clinics benefit from Belgium's public healthcare system, which ensures that public health insurance coverage keeps out-of-pocket costs for patients to a minimum. These clinics are usually well integrated into the social fabric of their neighbourhoods and often target socioeconomically disadvantaged populations. The individuals who attend the endometriosis consultation can be regular patients of the family planning clinic – usually people who menstruate and require contraceptive or reproductive assistance. *Infor-Femmes* also collaborates with other regional social healthcare centres (*maisons médicales*) to reach a maximum of people experiencing chronic pelvic pain. The *Infor-Femmes* clinic is easily accessible by public transportation from Liège's city centre. Notably, some women even travel from other parts of the country after hearing about this endometriosis consultation, usually via *Infor-Femmes*' social media accounts.

The social profiles of the women who attend the Endo consultation are diverse, including high school pupils, university students, working or unemployed women, mothers or child-free women **and even** asylum seekers. A significant proportion – about half – of those whose consultations were recorded were socioeconomically disadvantaged and/or had a recent immigration background **from a developing country**. Some of these women, or their families, struggled to afford medication or visits to private medical specialists, while others faced challenges navigating the

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Belgian healthcare system and experienced various forms of discrimination. To address these disparities, the clinic adapts to women's mobility and time constraints – arriving late to an appointment, such as due to public transportation issues, was never a problem. It also provides social support, offering guidance from social workers and referrals to inclusive and accessible healthcare facilities. The clinic's explicit goal is to ensure that neither financial resources nor time posed a barrier – medical certificates were provided to excuse a day's absence from work or school, allowing women to attend their appointments.

As part of the endometriosis pilot project, a patient who comes with issues of chronic pelvic pain is first invited for a psychology and/or sexology consultation. The patient then proceeds with a medical consultation dedicated to endometriosis screening by means of an extended anamnesis, possibly along with an examination (vaginal touch or ultrasound). Much effort is made to coordinate multiple professional perspectives. In general, each individual case is discussed among practitioners ahead of the medical consultation, which they will also discuss thoroughly afterwards for a consensus on the best therapeutic options. Hence, as soon as a woman crosses the door of the consultation, she has already entered a spatio-temporal arrangement ensuring she receives personalised care.

The medical consultation is planned to last for 45 minutes. This is a significant extension for Dr Tebache, whose consultation appointments, when she worked in a hospital, were limited to 20 minutes, minus the time needed to enter medical data into several software platforms (up to seven simultaneously). This said, based on recordings, we noted that the timing of the consultation is no longer the primary determinant of the therapeutic relationship, such as what happens when it is too constrained. Instead, the duration is subordinated to the patient's needs, sometimes shorter or longer than the indicative limit, depending on what needs to be expressed. **The duration of the consultation can act as either a constraint or a facilitator, enabling or disabling the relational, and thus therapeutic, potentialities.**

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Many of the stories shared during the anamnesis revolve around the long therapeutic journey women have gone through in search of a resolution to their chronic pain. In one case, H  l  ne, the patient at stake, is herself a nurse. She is therefore someone who cultivates a close relationship with the medical profession and the people who work in it. She has the vocabulary and resources to understand what is happening to her, and at the same time knows the specialists best placed to deal with the pain that affects her on a daily basis. She shares her distress with Dr Tebache:

I consulted several doctors, to no avail. I've been in the same condition for four and a half years. They can't figure out what's wrong with me. I have a strong inflammatory response. First I was asked to go to infectious diseases but I didn't really see what I was supposed to do there. I went anyway but assumed there was nothing infectious. I went to see a specialist to see if it was a pudendal nerve haemorrhage, and she told me it was, but I realised, after doing some research, that I didn't have all the symptoms. She didn't ask me all the questions in her anamnesis. Then, as I didn't really agree with the diagnosis, I went to see an abdominal surgeon, a specialist in pudendal nerve neuralgia, who ruled out this diagnosis because I feel better when I lie down and when I sit ... Dr X quickly closed the case. He hadn't seen the adenomyosis<sup>2</sup> ... Everyone takes care of their own thing ... I'm a fighter and I haven't given up, but most patients see the specialist who tells them that there's nothing wrong and that's it, that's the end of it ... They should redirect us.

Despite H el ene's expertise regarding her own body, none of the specialists she consulted was able to give her a correct diagnosis based on her anamnesis. She also points out that the lack of coordination between specialists sustains the 'non-existence' of endometriosis. Endometriosis tends to 'resist' biomedical classifications because the chronicity of the pain is cyclical and does not progress in a linear fashion – because it is hard to establish a classification for pain, and therefore to bring the symptomatic aetiology within a well-stabilised medical framework that would be equivalent for all cases (Denny 2009). The uncertainty that characterises the diagnosis, classification and evolution of the disease directly affects women's experience of endometriosis. As a result, therapeutic delay is a central feature of their relation to endometriosis. The feelings of distress, hopelessness and anxiety that women commonly experience can be partly attributed to dissatisfaction with healthcare (Culley et al. 2013). The French term for 'therapeutic delay' is *errance th erapeutique*: 'therapeutic wandering' in English. Women are frequently compelled to 'wander' through countless medical appointments with various specialists before their pain is legitimised and identified (Denny 2009). Despite their best efforts, they find themselves 'drifting' through a prolonged diagnostic odyssey. In our understanding, the notion of 'wandering' captures the struggle of the medical journey required to pinpoint endometriosis, as in H el ene's case. For these narratives to emerge during consultations, it is essential to provide a space where patients can articulate how their medical journey unfolded and how it led to their current situation. Stories of therapeutic or diagnostic 'wandering' abound in the

family planning clinic. For it is not only a question of delay but of misdiagnosis and misdirected treatment. This is the case of Amandine, now aged 41, who has suffered from regular pain since her first period around the age of 14. Over the course of the consultation, the screening confirms what emerged from a long discussion in which the patient described in detail her daily experience of this omnipresent pain, as well as the enduring uncertainty surrounding her symptoms:

I was told: it is the intestines. So I consulted a bowel specialist. But then, I say to myself, well, the pain, it could be normal. And there are the painful periods. But when I say painful, it's ... not every month. Sometimes it goes away and then sometimes I'm lying in the chair and I can't move. I gave birth, I had contractions and it's the same.

The anamnesis continues and the patient underlines the multiplicity of pains she suffers from and how difficult it is to ascertain their respective importance and prevalence. That question matters to Amandine as, depending on the answer received, the medical indication will vary:

I don't know if it's that [endometriosis] or something else. I don't know where the pain really comes from. I also have fibromyalgia. Is it this, or is it that? But this month the pain is in my groin. And I had a herniated disc in the past. The pain should have passed with the infiltrations but it still hurts. Now the doctors say I should have back surgery, but I prefer to look elsewhere before having my back cut open at 41.

Dr Tebache performs a vaginal touch and detects some endometriosis lesions. Amandine is astonished:

'And so at the exam you could tell that I have ... while I had ... It's crazy. If I hadn't looked for the solution myself ... And could it be that it also makes my leg hurt? I will not have back surgery, that's for sure ... It's crazy, I've been seeing gynaecologists since I was 15 and I tell them that I'm in pain, but no one has ever bothered ...' Throughout their therapeutic 'wandering' women become active managers and translators of their pain (Helosvuori and Oikonen 2024). Their attuning to bodily sensations is a distinct form of knowledge production: they constantly track changes and patterns in their pain, learn to compare and differentiate nuances of pain, and develop strategies to communicate their pain in a clinical context. However, this embodied knowledge is usually seldom acknowledged. Amandine's diagnostic 'wandering' is exemplary of

testimonial injustice (Fricker 2007), that is, the fact that her suffering was not heard and properly identified because of who she is – a woman. While it is still unclear whether endometriosis explains the multiplicity and chronicity of Amandine’s pains, one thing emerges out of the present consultation: the time taken to listen to the patient’s story allows the patient’s diagnostic ‘wandering’ to be fully acknowledged in looking for answers to her pain, so as to avoid unnecessary, even harmful treatments. Such an extended anamnesis creates an appropriate time-space for the endometriosis lesions to fully deploy and exist, in the extent of the pain they inflict and in their consequences for the patient’s life.

## Putting your finger on the spot: knowledge regimes and diagnosis

In this section, we show that when enough time is devoted to the consultation, it can accelerate the diagnosis and the medical response to chronic pain. Up until recently, the ‘golden standard’ of an endometriosis medical diagnosis was laparoscopy, a surgical intervention through which damaged tissues are sampled and then analysed to confirm, or reject, the presence of endometriosis (ESHRE 2022). Understandably, this invasive procedure is not routinely performed as a first intention, making ‘real’ diagnoses very rare. Today, medical imaging technologies are preferred, primarily endovaginal ultrasound and magnetic resonance imaging (MRI) (Millepied 2020). The latter is widely favoured in hospital protocols in Belgium. Ultrasound is less frequently used as a diagnostic method as it requires specific skills – however, it is Dr Tebache’s area of specialisation. That said, negative medical imaging results do not exclude the presence of endometriosis; therefore, empirical treatments are also recommended (for example, trying hormonal treatment and seeing if and how it alleviates pain). The following exchange between Dr Tebache and her patient, Laura, a young woman of 20, highlights the complexity of the condition and the many ways in which it can be *felt* and identified. At the first consultation, the family planning clinic had not yet acquired an ultrasound machine, so Dr Tebache performed a vaginal touch. An ultrasound examination was performed at Laura’s second consultation, where an endometriosis lesion was screened.

- So, is it diagnosed now, or not?
- For endometriosis, the official final diagnosis is histology. That means having the affected tissue in your hands, seeing it with your

own eyes, putting it under the microscope and analysing it. But in fact, the first time we met, without even an ultrasound machine, I thought you had endometriosis, because I touched it with my finger and it hurt you, and because it gets better when you take the hormone treatment. So, it depends on your point of view. For hard science, as long as you don't see the lesion, you don't have it. But for specialists, and for you, who are inside your own body, it is clear that you have endometriosis. So, we're going to treat you for that. ... Are you OK? [Laura sobs]

- Yes ... In fact, I'm relieved. Because it's been two years since ... Nobody believes me that much, you know. Is it possible to have a picture of the lesion? Can I show it to my parents?

- Yes, of course you can.

- So ... they can see it!

Two systems of scientific evidence coexist in the treatment of endometriosis. On the one hand, there is the system of biomedical evidence, which relies on a diagnosis made using technical equipment that detects lesions, objectifies complaints and documents symptoms (Dumes 2020). The machine, the technical tool, makes it possible to construct the data on which the medical intervention is based, and to do so in a short space of time. It is imperative to make the disease visible (Foucault 2015) by means of an image, indicators and parameters. This positivist system of proof is the system of the hospital, where knowledge is compartmentalised, distributed vertically according to stabilised hierarchical chains and asymmetrically between patient and doctor (Berg and Mol 1998). The system of biomedical proof – with its world of diagnoses, indicators and data – is therefore a prerequisite for obtaining access to treatment, reimbursement or, quite simply, societal recognition of a form of disability. However, this regime of evidence remains silent about the patient's living conditions, needs or life trajectory (Cohn 1999). On the other hand, at the family planning clinic, other sensorial and experiential systems can provide an account of the pervasive existence of endometriosis in a patient's life (Dumes 2020): the sense of touch and the pain the patient associates with it, the careful listening to the patient's story of their symptoms.

At the time of the first consultations, the family planning clinic had not yet acquired the medical imaging equipment for screening endometriosis. This forced Dr Tebache to revive practices that had been neglected and rendered obsolete over time due to overreliance on technology, such as vaginal touch. She relearned how to identify endometriosis through the sense of touch, delicately feeling the lesions with her fingers. We

could call this technological minimalism. In our understanding, such minimalism makes room for the relational aspects of care, with simpler, less costly procedures and a different distribution of knowledge. The effect of this approach has been to increase the amount of time available, moving away from a focus on technology alone and towards listening to the patient's needs.

An ultrasound can show many things but not a patient's history. During consultations, experience remained at the centre of the diagnostic process. The following excerpt describes Coralie's situation. Aged 30, she has suffered from regular pain since her first period, from the age of 14. Dr Tebache carried out an ultrasound examination, which showed endometriosis lesions. Coralie was overwhelmed with emotion at the news that lesions could be seen – that they did exist. When Dr Tebache asked her how she felt about the news, she replied:

If I'd been given any kind of answer, I'd have cried. If someone had said 'that's it', I would have cried. If someone had said 'that's not it', I would have cried. I've been waiting for so long for someone to take into consideration the fact that I am in pain during my periods. I find it incredible that it's taken so long for someone to listen to me.

Whether or not endometriosis is present, what matters to Coralie is that someone has listened to her. In the family planning clinic, the eye that sees is now joined by the ear that listens. Listening to the patient, her needs and her desires lies at the heart of the consultation. In this case, it is not so much the visual observation of a lesion that matters than the account of an experience – of the conditions of living with it, of what it prevents or what it makes inevitable. This way of diagnosing is both more sensitive and more perceptive. It opens up the time of sensations and provides multiple instances for perceptions; in addition to the time for seeing, there is also a time for touching, a time for hearing. In that sense, it is an expansion of the perceptual sensorium of medical imagery, which is made possible only by welcoming a greater diversity of evidence, or what counts as such. The aim of our approach is not to substitute experience for scientific proof, but to show that they complement each other. It is a question of no longer seeing machines as the only means of constructing medical proof. In that sense, the Endo consultation attempts to bridge the 'tension between the growing emphasis on symptoms as the basis of treatment and the long-standing epistemic privileging of visual verification as "real" evidence' (Helosvuori and Oikonnen 2024: 951). These epistemological regimes are not antagonistic; they can coexist

and reinforce each other within an endometriosis management protocol aimed at improving the patient's living conditions.

## Chronic neglect and possible futures: proposing treatment

At the family planning clinic, the choice of treatment does not depend on the size or number of lesions visualised. It depends on how patients experience pain and how it affects their specific life trajectory. It is only by placing pain in a long-term perspective that a range of treatment options can be sorted out. In addition, the consultation itself provides an opportunity to name and acknowledge various forms of violence that may have been experienced. The intrusion of life stories into the medical realm creates a space-time in which bodily aches and psychological suffering are both legitimate and can coexist. This does not imply that body pains are directly caused by psychological distress, nor that psychological distress is solely a consequence of body pains. Rather, beyond the singularity of the pain experienced, the two excerpts analysed below show how several forms of social inequality intertwine in the experience of chronic illness (Macgregor et al. 2023), accompanied by various forms of psychological and physiological harm. We here attempt to identify the social underpinnings of living with endometriosis by showing how, in the family planning clinic, women's social realities are incorporated in the process of choosing a treatment plan.

At the start of the consultation, Farah, aged 35, announces in a trembling voice that she had been subjected to incest as a child and had recently experienced domestic violence at the hands of her current husband. She is also subject to severe pelvic, urinary and back pain, the cause of which has not been found by the various doctors she has consulted: *'My general practitioners didn't want to believe me about my cervical and lumbar pain. They said: "it's psychological, go and see a psychiatrist".'* Farah also mentions her wish to remain childless. Dr Tebache then suggests that she have an endovaginal ultrasound, although Farah seems very uneasy about it at first. She eventually accepts the ultrasound; Dr Tebache takes the time to explain everything she will be doing and remains attentive to Farah's feelings during the examination.

- We may have found some explanations for your pain. There's a bit of what's called adenomyosis and a bit of what's called endometriosis. I also see a strong contraction of the perineum.

- So, I'm not crazy.
- No. The size of the lesions does not predetermine the strength of the pain. Then, as a result of being in pain all the time and in addition to your past history, you have very tight muscles around the vagina.

Dr Tebache then proposes a hormonal treatment that would block her periods and reduce the pain. She also suggests that Farah begin physiotherapy to relax her perineum once she feels psychologically ready.

- So, firstly, these stories are not in your head. Secondly, what you've got isn't too extensive, so don't panic. Thirdly, I must congratulate you, you've been very brave. It's a very good sign that you're taking yourself by the hand and moving towards the day when you'll be healthy, happy and pain-free.
- ... But the doctors said it was psychological.
- No, it's not psychological.

The health professionals Farah had consulted disqualified her pain. Referring her to a psychiatrist had the effect of suspending the credibility of her pain and hence its legitimacy. The diagnosis made during the consultation anchors Farah's pain in a materiality upon which she can now act. The context of the violence – sexual and medical – she had suffered informed the nature and scope of the proposed treatment, which was as less invasive as possible (hormonal treatment and physiotherapy).

Erica, on the other hand, is 40 years old. She has had severe pelvic pain since she started menstruating. When she was 20, she underwent laparoscopic surgery to remove cysts, but she was never really informed about the exact reason and outcome of that surgery. Her pain has intensified since she separated from her partner and father of her child four years ago. Over the course of the conversation, Erica talks about her feelings of exhaustion and loneliness.

- Do you feel a bit alone in managing your responsibilities at the moment?
- I feel alone when I suffer. My family is far away and I live here alone with my son. He's my daily worry and I want to take care of him, but when I'm in bed because of my pain, he does everything on his own.
- What do you do for a living?

- I don't work, which is another reason why I jumped at the chance [to come for a consultation]. I've been very ill for the last two years and I'd like to be able to work without having at least one major crisis a week. I don't know how I could explain that to the employer when I apply for a job ...

- You want a new life and you're stuck.

- I'm stuck and I'm asking myself a lot of questions. Will my employer agree to me being on a week-long leave every month?

The ultrasound examination reveals indicators of endometriosis and adenomyosis. Dr Tebache suggests surgery, as hormonal treatment was not reducing Erica's pain. Furthermore, Erica shares that she might like to have another child if she were to meet the right person; surgery could increase her chances of becoming pregnant.

- But would surgery guarantee that I won't have any more pain, or ...

- It's never a 100% guarantee. But it's clear that if we don't test, we'll never know what the resolution is. The main reason for surgery is to improve quality of life. That's for you to decide. It's up to you to say to me: I can't live properly, so yes, I'd like to have the operation, or not. Now, you don't have to answer that question right now. We can meet again when you want, when you've thought it over.

- I don't know [Silence]

- Well, not knowing is already an answer. It means we need time.

Erica asks a few questions about the surgery, including how long she would have to stay in bed and whether she would be able to look after her son while she recovers. She says:

- I think I'll have the operation, at least for, er ... That's what I'm going to cross out, in fact, in the solutions ... I'm going to cross that out because ... [her voice breaks] Yes, I'm going to have an operation ...

Erica seems to be stuck in a life trajectory that prevents her from fully pursuing the activities that are important to her: working, looking after her son, having a social, sexual and emotional life. Surgery offers the possibility of a fresh start, or at least an attempt. New temporalities collide: her therapeutic 'wandering' meets futures that suddenly open up. In both Farah's and Erica's cases, while the diagnosis validates the patient's past experience, the proposed treatment is a way of outlining a future the patient desires and hopes for. It offers new modes of *anticipation*, here

add « more satisfying » here otherwise it may read as she has no social, sexual and emotional life at all and that's obviously a stretch from the excerpt

understood as an ‘affective state, a way of actively orienting oneself temporally’ towards possible futures (Adams, Murphy and Clarke 2009: 47).

In both excerpts, the consultation space provides an opportunity to pick up on the language of the body. The body language reflects the violence or social difficulties experienced (the vaginal contractions in Farah’s case and Erica’s state of total exhaustion). The treatment proposes to address the varied problems identified during the consultation: physiological, social and psychological. In both Farah’s and Erica’s cases, the medical profession has *chronically neglected* their experience of illness. These two accounts allow us to move on from the singular experience of illness to a politicisation of that experience; we can then outline the wider structural dimensions that shape individual trajectories. The neglect they face takes the form of epistemic injustice; it both results from and perpetuates gender inequalities. On the one hand, Farah’s therapeutic delay seems to emanate from the gender biases shaping Western medicine (Seear 2014). Having failed to find physiological evidence for her pain, the medical profession relegates her experience to the psychiatric domain. This echoes the systematic pathologisation of the bodies or attitudes of women who fall outside the established norm. For instance, both endometriosis and hysteria share the underlying assumption that women are unstable, deranged and unable to stand pain (Jones 2015). On the other hand, the chronicity of Erica’s condition and its lack of recognition prevent her from participating fully in social life, thereby deepening inequalities (inability to work, social isolation as a single mother). As a result, the dismissal of women’s pain lengthens the therapeutic delay and reinforces isolation. This leads to chronic failure to account for the many ways in which endometriosis affects women’s lives and, also, affects them in very different ways, since both Farah and Erica have quite different expectations regarding the lives they want to live, their aspirations and hence their diverging therapeutic needs.

## Discussion

Throughout this chapter, we have seen multiple temporal regimes, each distinct yet deeply interwoven. These include the temporalities inherent to the time-space of care: the inertia of hospital protocols and therapeutic delays, the varying times allotted for medical consultations and the layered temporality of the endometriosis frontline screening. During the consultations we have described, diagnosis becomes a moment where these temporalities converge, bringing together painful pasts and

hopeful futures. This is the reason we must move beyond the routine reliance on medical imaging alone, which merely offers a static snapshot of a body taken in isolation. Endometriosis, in contrast, requires recognition of **its history**, a genealogy entangled with the complexities of lived experience and futures that may be (un)desirable. The family planning clinic recalibrates the perception of time passing, already fragmented earlier by the therapeutic ‘wandering’ of women seeking answers for their chronic pain. The ‘thickness’ of the consultation time results from the fine tuning of different temporal layers in the patient’s lived experiences.

replace by « this body’s history »

Temporal hiatuses weave into forms of epistemic injustice within the biomedical framework for endometriosis care. These injustices contribute to therapeutic delays and a diminished quality of life. First, in the pursuit of a diagnosis, a woman’s pain is often dismissed, invalidated or relegated to the psychiatric domain. Second, priority is given to visible lesions over the patient’s expressed symptoms when making a diagnosis. Third, the uncertainty surrounding the condition prevents women from acquiring meaningful knowledge about their bodies or envisioning a hopeful future. These instances of epistemic injustice are profoundly gendered, perpetuating the chronic neglect of women’s experiential knowledge.

The family planning clinic’s frontline approach not only offers a means to recalibrate time, but it also serves as a juncture where different epistemic regimes collide, opening up to different sensitive and perceptive regimes while making lived experiences medically visible. In this process, the clinic’s approach is not necessarily a stance in opposition to the biomedical framework; both perspectives could work in tandem. Early symptom detection can lead to appropriate medical interventions when necessary.

However, this discussion also anticipates a future challenge that healthcare professionals concerned with endometriosis may soon face: the development of saliva testing as a diagnostic tool. This is precisely the promise of Ziwig,<sup>3</sup> a French start-up that has created a saliva test capable of detecting endometriosis within a few days. This technology promises to drastically reduce diagnostic delays by offering a fast and seemingly unmediated diagnosis of the condition. However, it might also lead to a ‘statistical explosion’ in the prevalence of endometriosis within the population. This statistical phenomenon will not necessarily provide us with valuable information on endometriosis and its lived consequences, given that endometriosis lesions can be perfectly asymptomatic.

While the saliva test holds great potential for women seeking a quicker diagnosis, we caution against its use as a shortcut that bypasses the ‘thick time’ required to develop a meaningful therapeutic relationship. As we have demonstrated throughout this chapter, *speeding up* diagnostic processes does not inherently improve the quality of care (Sanz 2017). Paradoxically, quicker detection may lead to further delays in accessing effective treatment. *Slowing down* the consultation process, spending time exploring various aspects of the patient’s life, taking more than one appointment to reach a diagnosis and continually readjusting the treatment to the patient’s fluctuating experience of pain can reduce therapeutic delays and improve quality of life.

There is also a broader dimension to the frontline screening approach. As an experimental dispositif, it encourages us to question the temporal and spatial conditions that underpin the production of health and well-being on a larger scale. Framing the issue in this way invites engagement in a broader chronopolitical project: which temporalities empower us, and which dispossess us? There is no singular, absolute answer to such a question. Yet, as we have shown throughout the chapter, there are different versions of ‘thickness’, as in ‘thick temporalities’ that can take root in the interplay of different temporal regimes. Thickness occurs when the past pushes its way into the present, when the present opens itself to other perceptive and sensory signs, or when the future reopens different implications of what ‘caring’ means and to whom, depending on each person’s desires and aspirations. It is within the intersections of these heterogeneous and sometimes conflicting temporalities that the potential for political action emerges.

## Notes

1. *Collectif Endo plurielle*: Lucas Bechoux (University of Liège), Lucie Destiné (Planning Infor-Femmes), Luce Lebrun (FNRS, University of Liège), Shana Riethof (FNRS, University of Liège), Linda Tebache (Planning Infor-Femmes) and François Thoreau (FNRS, University of Liège).
2. Adenomyosis, often referred as endometriosis’s ‘sister’, occurs when the inner lining of the uterus (endometrium) grows into the muscular wall of the uterus. The main symptoms are heavy menstrual bleeding and chronic pelvic pain.
3. <https://ziwig.com/en/home/>. Ziwig’s aim is ‘to transform women’s health with salivary RNA and artificial intelligence’ (accessed 15 November 2024).

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