

How to Categorise Disease?

Endometriosis, Inflammation, and ‘Self Out of Place’

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Abstract

Endometriosis is a condition where tissue similar to the uterine lining develops outside the uterus; it ‘bleeds’ during periods, forms lesions, and causes chronic pain. Despite affecting around 10% of menstruating people, its aetiology is poorly understood, and diagnostics and treatments are highly inadequate. Current efforts to reconceptualise the disease generally centre around inflammation. In this Field Note I describe my fieldwork during the pandemic, which was largely based on in-depth interviews with patients and clinicians in and around Edinburgh, Scotland. This research interrogates the socio-cultural context in which endometriosis is changing from a ‘gynaecological disorder’ to a ‘systemic disorder’ implicating the endocrine system (a ‘hormonally driven condition’), the neural system (‘neuropathic pain’) and/or the immune system (an ‘inflammatory condition’). It explores how the lived experience of endometriosis challenges ingrained ways of thinking about the body and bodily ‘systems,’ which are reflected in the design of healthcare systems. Considering endometriosis alongside changing conceptions of immune response invites thinking beyond self-versus-non-self (as in older concepts of immunity), and self-attacking-self (as in auto-immune conditions), to something like ‘self-out-of-place,’ simultaneously calling into question the suitability of our social and material relations.

Keywords

Endometriosis, Categorisation, Environment-disease connections, Gendered disease, Chronic disease.

It was over Zoom, of course. Pandemic research. But the pain and anger was still palpable in the digital ether. Elsa and Kim were together in this interview's group call because they did a lot of organising and activism together. Their stories resonated with each other and built momentum, merging into a behemoth by the end of our two-hour long conversation. The women's physical pain was evident—one lay in bed with a hot water bottle—overlaid by the outrage of not being believed, of having to work *this hard* to get anywhere with their chronic illness. Tears and apologies for tears.

I listened, as empathetically as I could in virtual form. I tried to ask sensitive questions and offer them a receptacle for their stories and their anger. I tried to offer them time, which is in such short supply in clinical encounters. I tried to bear witness to their pain without trying to explain it, fix it, or hide it. My own periods barely register with me as a disturbance of any kind, unlike these women whose endometriosis is debilitating for much of the month. I tried to keep my feelings of guilt in check.

When reflecting on these interviews, I sometimes feel silly fussing over how endometriosis is categorised when people are in agony. But the categories do matter, I tell myself. They're in part why adequate treatments and biomarkers and education programs don't exist yet. They're implicated in why the medical system works for some, and not others. They underlie how hard it is to get research funding, and the shame and bewilderment surrounding symptoms. Because what is endometriosis, anyway?

The medically correct explanation is that it is a condition where tissue similar to the uterine lining develops outside the uterus; this hormonally-responsive tissue 'bleeds' during periods, forms lesions, and causes chronic pain. During my research, a clinician described it as 'mini periods outside the womb'. Despite affecting around 10% of menstruating people, endometriosis is under-researched and its aetiology is poorly understood (Horne et al. 2017). My fieldwork consisted of in-depth interviews with six clinicians and thirteen people with endometriosis in and around Edinburgh, Scotland, who ranged in age from early twenties to septuagenarian. I attended support groups, medical conferences, and followed online forums throughout 2019–2023. I consider medical literature a 'fieldsite', too, which I read with an eye for metaphors, contested framing, and instances where scientists push against traditional conceptualisations of endometriosis and related conditions.

Is endometriosis a menstrual disorder, as it is often described? This moniker leads to the dismissive idea that endometriosis is 'bad period pain', which came up frequently in my interviews and notes. As a debilitating chronic illness, it's so much more than that. It often persists when a person is not menstruating, and even after

a total hysterectomy. Lesions of out-of-place tissue can be found all throughout the pelvis and as far as the lungs or brain. Qualitative research paper titles like “A day-to-day struggle” (Hawkey et al. 2022), “My body is out to wreck everything I have” (Mills 2022), and “The most lonely condition I can imagine” (Cole et al. 2021) suggest the extent of its impact. Such phrases were common in my interviews, too. I always began by asking people how they would describe what endometriosis is to someone who hadn’t heard of it. Mary said,

Painful, would be my first word. And life-controlling, not wanting to freak anybody out if they’ve just had a diagnosis with it, for example, or if they didn’t know what it was. But very, very painful periods. Not even just periods really, throughout the month, pelvic pain to the point where it takes over your life [emphasis added], especially for me.

Is it a reproductive or fertility disorder? It certainly can have consequences for fertility, but these are uneven across people with endometriosis. Calling it a fertility problem also plays into the troubling, persistent idea that pregnancy can ‘fix’ it and that women’s fertility matters more than their pain (Freedman 2016). People with endo, as it is often called in patient communities, frequently report finally receiving attention and sympathy when they express that they wish to conceive, but not when their daily experience is intolerable. This held true across my research. One support group meeting involved spiralling anger about this, among people who were young and didn’t want kids yet, someone who just told her doctor she wanted to conceive, someone who had been struggling for years to become pregnant, and the group leader who dismissed pregnancy as an option for herself. To be sympathetic to physicians, medical practices often only have something to offer to treat fertility, not chronic pain—and we circle back to which problems are considered important to research. The common slippage between ‘reproductive’ and ‘women’s’ health is a problem in and of itself (see Almeling 2020).

Is it even a women’s or gynaecological disorder? Usually, but trans men and non-binary people, and even a tiny number of cis men can have it (Al-Obaidy et al. 2019). Moreover, calling it a ‘women’s problem’ ushers it into the well-worn grooves of something ‘niche’ and vaguely embarrassing, despite being as common as diabetes. Elsa and Kim, from the opening anecdote, shared frustration at the social dismissal of problems associated with women:

There’s this, you know, taboo around it being a woman’s problem and ... if you see our tweets and our social media, we want people to think outside the box here, you know, because it shouldn’t just be considered a woman’s problem. We are an integral part of society. We are women and we should be proud to be women, but we carry your children, we run your houses, we do lots of amazing things over and over again, multitasking continuously. But yet, when

you get something like this, you're somehow put in a box of 'she's not really worthy,' or 'she's weak,' or 'what a melodramatic woman she is,' you know, and some of that shame and that hurt can come from your fellow women as well and you're like, wow, where did this come from, what have we done to deserve this. This isn't a bad period, guys.

Some biomedical scientists are pushing against this in the way they brand their research labs, emphasising the remarkable regenerative and immune properties of the uterus, endometrium, and placenta to advocate for their relevance to medical science's 'big questions' (Gross 2021).

Categorisation matters for diagnosis: it frames the disease. The importance of receiving a timely diagnosis in terms of patient experience is often emphasised in public awareness materials, as the average time to diagnosis in the UK is eight years, during which people report feeling bewildered, disbelieved, and ignored. Talia had just been diagnosed when I interviewed her, and she stated that 'getting the answer and getting some sort of relief and getting the diagnosis was the biggest issue, because it caused so many problems and so much heartache to get there.' But diagnosis matters in terms of what *kind* of disease is being diagnosed, too. Every patient I interviewed reported feeling passed around like a hot potato from specialty to specialty, and this didn't necessarily end once they had a diagnosis. Talia had severe bowel problems due to endometriosis and spent over a year being sent to a gastroenterologist who repeatedly told her nothing was wrong—Talia said that the stress of the diagnostic run-around had been making the symptoms worse. Diagnostic categories help pin down what causes a problem, how to fix it, and 'where' exactly is wrong—yet endometriosis transcends and complicates standard ways of assigning diseases to healthcare facilities and specialties.

Increasingly endometriosis is being classified as a 'systemic' disorder. Generally, 'systemic' means the whole body, transgressing the anatomical systems that organise Western medical traditions. Endometriosis is frequently narrated in terms of other, more diffuse systems, such as the endocrine, neural, and immune systems, alongside the genetic and epigenetic dimensions of health (e.g., Balasubramanian et al. 2021; Montgomery and Giudice 2019). My notes and interviews with clinicians are littered with the phrases 'hormonally driven', 'neuropathic pain', and 'inflammatory condition'. Taylor, Kotlyar, and Flores describe how endometriosis affects metabolism in liver and adipose tissue, leads to systemic inflammation, and alters gene expression in the brain that causes pain sensitisation and mood disorders. They write, 'The full effect of the disease is not fully recognised and goes far beyond the pelvis' (2021, 839). Some medical papers go beyond so-called sex hormones to examine how cortisol and oxytocin influence

endometriosis, advocating more serious consideration of ‘mind-body interactions’ (Dinsdale and Crespi 2017). Perhaps, I think, ‘systemic’ could even acknowledge the social and environmental soup that surrounds and composes our bodies, transgressing the illusory skin-boundary, framing disease as an accumulation of experiences that extend well beyond the unitary individual, and rendering the Cartesian mind-body split nonsensical. But this is an anthropologist’s counter-fantasy.

I asked all my interviewees, both clinicians and people with endometriosis symptoms, about their thoughts on possible classifications. ‘Do you think of endometriosis as a genetic disorder? A hormonal one? What about an environmental one?’ This last one caught most non-clinicians off guard. I started to hedge the question, asking first if people had heard of endocrine disrupting chemicals, or EDCs. Most hadn’t. As I would gently explain, we live in environments saturated with synthetic chemicals that can mimic or disrupt hormonal processes. They’re found everywhere from industrial and agricultural by-products to manufactured goods to pharmaceuticals. Biomedical research associates such chemical toxicities with negative reproductive outcomes and chronic health problems, including endometriosis (e.g., Louis et al. 2012), though it is notoriously difficult to isolate and prove chemical causes. I began my research interested in how people made sense of this environmental piece of the puzzle. It turns out that it wasn’t really on most people’s radar. Mary was one of the few who had heard of EDCs:

[I know the term] because I like to read up a lot about stuff but again I’ve not found a lot of information really. Because I’ve thought surely there’s something that’s a bit more in-depth of why women suffer like this but I’ve not been able to find much ... I’m a vegetarian and I very much try to be organic and stuff where possible ... you can’t obviously get rid of everything because it’s all around you all the time. Even in teabags, it’s like stuff you can’t escape it. But wherever possible I’ve tried to cut out the crap, basically trying to have kinder washing up stuff sometimes ... there are all these xenoestrogens or something out there, that don’t help with the brain.

Mary’s engagement with the environment centres on organic food and cleaning products, an individualised consumer ‘politics of purity’ that was ubiquitous among non-clinician interviewees when I brought up chemicals (Ford 2019).

It isn’t at all surprising that chemical toxicities were not front and centre, given the persistence—and indeed, intensification—of individualising approaches to pretty much all problems, not least those relating to health (Rose 2007; Crawford 1980). Clinicians were aware of endocrine disruption, but largely found it troublesome to investigate or talk with patients about, given how it requires a totally different, non-

individualised approach to action (Liboiron, Tironi, and Calvillo 2018). Categories of disease, illness, and disorder are not straightforwardly determined by that which we call 'nature' or a direct reflection of it; rather, diseases are defined through social negotiations that reflect interested and situated perspectives (see e.g., Dumit 2006; Swallow 2020). And it is in the interests of the systems-that-be to frame diseases as properties of individuals.

But if hormonal function is being disrupted in constant small ways due to our environmental contexts, and hormones drive inflammatory response, and inflammation is key in current efforts to reconceptualise endometriosis ... then why not think of endometriosis as an environmental disorder? This is an interpretation that has been contested and marginalised, and consequently hasn't gained traction (see Capek 2000). Some research suggests that trauma, particularly during childhood and early sexual encounters, correlates strongly with endometriosis (Hawks et al. 2019; Reis et al. 2020). Experiential trauma is thought to have profound and long-lasting effects on the 'stress system' which encompasses hormonal and inflammatory responses (see research on adverse childhood experiences (ACEs), e.g., Filipe, Lloyd, and Larivée 2021; Roberts 2015; Pennebaker and Susman 1988). Research on epigenetics explores how environment and experience affect gene expression (e.g., Müller et al. 2017); the possibility that such changes might be heritable is often problematically framed via a politics of maternal responsibility (see work on the developmental origins of health and disease (DOHaD), e.g., Sharp, Lawlor and Richardson 2018; Valdez 2018). What exactly are the differences between an environmental disorder, an experiential disorder, and an inflammatory disorder?

Maya, an interviewee with endometriosis, wondered about such things too.

But I think, I truly believe that, as with other diseases, there are environment factors that affect. So I believe this is why some people experience endo so differently, so it depends on your diet, on your health style, on different things, on your level of stress. And for me the trigger was when I was working in a very, very stressful environment and I was at my limit, and this is when I started to have these extreme cramps, and ... yeah. So it's not that we can get rid of stress totally, because it's the world we live in, and my career also is very demanding in this way. But I think we can find ways to try to manage this; so I quit my previous job and then we moved here.

She continued to mention toxins in food and how she was trying to have a more organic diet because of pesticides. When I asked her to say a bit more about toxins in the environment, she brought up pollution, and quickly re-emphasised stress. In her words:

... stress is the most terrible trigger, I think, because where I used to live before, in Brazil, it was not a safe place; so it's like your body is stressed all the time, like you were waiting for the danger and something could happen any time. So this creates a continual stress and continual inflammation in your body.

I asked her whether she considered things like stress or toxins as hormonal problems, and she went on:

Well, I think everything affects in a way our hormones. So from your sleep quality ... our food, and the stress, the light, the pollution, I think; so yes, I think most of these inflammatory diseases come from this environment we live in. So for example, my mother has Hashimoto's [an autoimmune disease], so it's her own body attacking [her] thyroids; so it's probably something with the environment, the stress ... we have all these expectations and things in our lives, and somehow we don't learn how to manage this in a good way. So yes, I think [endometriosis] is a conjunction of many factors and resulting in the inflammation and altering our hormones.

This nexus makes me wonder not only about recategorising endometriosis, but about how immune function itself might be framed differently—and indeed aetiology, and even disease. With a few exceptions, such as Maya, such arcane musings are not what people with endometriosis discussed in interviews, nor did they feature in support groups or on forums. But as I work through my field notes I notice the many ways quotidian practices of symptom management participate in debates about categorisation.

Many in endometriosis communities advocate and follow anti-inflammatory diets, for example. As we've seen, a few people I spoke with considered organic foods to be important. Someone else mentioned her strategies around phytoestrogens (estrogens derived from plants, like soybeans). Almost all interviewees took various measures to mitigate their stress levels, including drastic ones like cutting ties with family, as their endometriosis flared up under stress. Hormonal wellness self-help books, courses, and podcasts often discuss endometriosis alongside period management. In these forums, there is lively debate around the benefits, utility, and side effects of hormonal birth control, which is very commonly prescribed as a first-line medical attempt at symptom suppression (some clinicians I spoke with noted that its success often contributes to delayed diagnoses). Much as people would like a straightforward cure, such practices and discussions push against the 'cut it out' thinking that dominates biomedical approaches. Hysterectomy (the total removal of the uterus and sometimes also the ovaries) is a traditional, anatomy-based surgical 'treatment' that has come under fire from patient communities because it rarely works despite being incredibly invasive.

Even the ‘gold standard’ of laparoscopic surgery to remove the endometriosis lesions is increasingly viewed as problematic as their presence and extent does not correlate with the severity of pain experienced, and sometimes the disturbance effected by surgery can worsen symptoms (Osborne-Crowley 2021).

The lived experience of endometriosis challenges ingrained ways of thinking about reliable evidence of disease—that is, as made manifest by the material body instead of the accounts of those experiencing it (Foucault 2012). It also challenges the design of many healthcare systems, which reflects ingrained thought patterns about bodily systems. Griffith (2018) coined the term ‘a-diagnostic category’ to describe how many patients have ‘been given an explanation for their symptoms but such explanations remain non-medicalised such that subsequent treatment is not given’ (ibid., 32); their experiences baffle what medical systems have to offer. It is pre- or sub- diagnostic. It is a no man’s land. A dead end. A write-off.

What would it look like to reimagine endometriosis by centring the immune system, not as a discrete function within the body, but as an interlaced set of relations between endocrine, neural, and (epi)genetic systems? How might endometriosis, alongside emerging understandings of immunity, be understood as a conversation enacted across multiple dimensions of knowledge and experience (Napier 2012; Biss 2014), as a delicate litmus test for the suitability of our social and material environments? There are a few moves in this direction, such as new research revolving around patients’ dietary strategies and clinics organised around symptoms instead of traditional disease classifications (for example, around ‘chronic pelvic pain’; see Hickey, Missmer, and Horne 2020). Endometriosis cannot be described as self-versus-non-self, as in classic metaphors of immunity, nor even as self-attacking-self, as in auto-immune conditions. Rather, it invites something like ‘self-out-of-place’, as lesions go rogue throughout the body. Some interviewees described it as a cancer: self becoming non-self; a turncoat; a traitor. What is this but a question of relations?

Authorship statement

I am the sole author of this work, and offer gratitude to those who shared their experiences and thoughts with me.

Ethics statement

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