Navigating Pharmaceutical Effects: Experiences of Hormonal Medications in Endometriosis

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Abstract

Endometriosis is a chronic illness often treated with hormonal products, such as oral contraceptives or hormonal IUDs. As many hormonal products have side effects, and both side effects and effectiveness can be unpredictable, people with endometriosis try to find, often through trial and error, a medication that is tolerable yet effective. Drawing on interview and story data collected in Finland, the article explores how people with endometriosis perceive the multiple effects of hormonal pharmaceuticals and how they make decisions about what medications to try or continue. The article identifies three issues that characterize experiences of living with and managing endometriosis: 1) establishing hormonal contraceptives as key medications while also critiquing the lack of attention paid to side effects; 2) approaching side effects and effectiveness as relational through comparison of treatments; and 3) negotiating the limitations on choice that arise from age, other diagnoses and availability of pharmaceuticals.

Keywords: Endometriosis, Choice, Chronic Illness, Hormonal Medication, Pharmaceuticals, Side Effects

Introduction

Hormonal pharmaceuticals, such as oral contraceptives, are widely known to cause side effects. These range from relatively common problems such as acne, mood symptoms and weight gain to rare but life-threatening complications such as thromboembolism (Barbara et al., 2021; NHS, 2022). While a person choosing a contraceptive can opt for non-hormonal methods, the question of choice becomes complicated when hormones constitute a part of medical treatment. This is the case with endometriosis, a chronic gynaecological condition that is often described as affecting around 10 percent of women (Chapron et al., 2019; Hudson, 2022; WHO, 2023). Endometriosis is an oestrogen-linked condition characterised by growth of tissue similar to the lining of the uterus in, for example, ovaries, intestines or other organs. Changes in oestrogen levels during the menstrual cycle cause inflammation around endometriosis tissue, resulting in severe, prolonged pain and other symptoms (Chapron et al., 2019; Hudson, 2022; Vannuccini et al., 2022). Hormonal pharmaceuticals are used to control oestrogen levels in order to alleviate symptoms and, ideally, slow the progression of illness. There are people with endometriosis who do not use hormonal medica-

tions because their symptoms are mild. Likewise, there are patients who find hormonal medications ineffective as their bodies do not respond to the most common hormonal treatments (Chapron et al., 2019). There are also many who use hormonal medications without any side effects. Yet, for many people with endometriosis, hormonal pharmaceuticals constitute an area of complex, situated negotiations as to which products to use, how and when to use them, and what consequences not using them might have for the illness.

Until recently, surgery was considered a primary treatment for endometriosis as well as a means of confirming diagnosis (Vannuccini et al., 2022). However, endometriosis surgeries have been associated with complications such as nerve damage or relapses (Berlanda et al., 2017; Vannuccini et al., 2022). Today, hormonal products often appear as a less invasive option, as hormone therapy can be discontinued or replaced if needed. Treatment protocols have highlighted hormonal products as a means of delaying the need for surgery and of preventing a post-surgery relapse (Berlanda et al., 2017; Chapron et al., 2019; Vannuccini et al., 2022). In the context of my study, Finland, an overview of endometriosis published in the Finnish Medical Society Duodecim's online library lists surgery as a recommended treatment only in certain subtypes of endometriosis (Tiitinen, 2023).

Although endometriosis is common, there are few medications or therapies developed specifically for its treatment. This lack of biomedical attention has been attributed to the long-term underfunding of research on women's health (Griffith, 2020; Hudson, 2020; Seear, 2014). Hormonal pharmaceuticals most typically used in endometriosis include combination contraceptive pills (with oestrogen and progestogen), progestogen-only contraceptive pills and hormonal IUDs (Chapron et al., 2019; Vannuccini et al., 2022). Since endometriosis symptoms tend to be particularly severe during periods, contraceptive pills are often used without breaks to maintain steady hormonal levels and to remove periods. Other pharmaceuticals, such as gonadotropin-releasing hormone analogues (GnRHa), which temporarily suppress ovarian activity, are also prescribed (Chapron et al., 2019). However, as all these hormonal medications have a contraceptive effect, they are not suitable for endometriosis patients trying to get pregnant. At the same time, the effectiveness of hormonal medications in endometriosis is often uncertain and can be found out only by trying different products, many of which are prescribed off-label (Griffith, 2020; Vannuccini et al., 2022). Likewise, the side effects they produce can be unpredictable. The situation is, of course, not unique to endometriosis: there are many conditions with limited treatment options where choices are made, often through trial and error, between less-than-ideal medications.

The article explores how people with endometriosis negotiate the complex field of desired and undesired effects of hormonal pharmaceuticals. Based on interview and story data collected in Finland, the article asks: How are the embodied effects of treatment options felt and choices between pharmaceuticals made when living with endometriosis? The analysis centres on non-life-threatening side effects, which may be considered mild by clinicians but shape a person's life significantly when used for an extended time. This focus makes visible how the invasiveness of treatment (e.g., De Marco et al., 2024) is experienced as a multifaceted issue that extends beyond surgical intervention to the long-term hormonal moulding of mind and body.

Social scientists have examined women's experiences of side effects associated with hormonal products as well as documented the history of medical and pharmaceutical institutions' dismissal of those experiences in the context of contraception (Bertotti et al., 2021; Bertotti and Miner, 2019; Kammen and Oudshoorn, 2002; Littlejohn, 2013; Littlejohn and Kimport, 2017; Oudshoorn, 2003; Schneider-Kamp and Takhar, 2023; Siegel Watkins, 2011). Social scientific studies on endometriosis, in turn, have explored delayed diagnosis and problems with accessing care as well as medical and social dismissal of endometriosis symptoms (Bullo, 2018; Denny, 2009; Griffith, 2020; Hudson, 2022; Jones, 2016; Markovic et al., 2008; Seear, 2009, 2014). While hormonal medications and their side effects are often mentioned in endometriosis literature, there is a need for a detailed analysis of the ways in which people with endometriosis navigate pharmaceutical effects.

The article begins with a discussion of social science research on pharmaceuticals and side effects. It then introduces the analytical framework, which foregrounds the ambiguity of choice in chronic illness. The three findings sections that follow explore three issues that, I argue, structure the views of hormonal pharmaceuticals expressed in my data: 1) establishing hormonal contraceptives as key medications while also critiquing the lack of attention paid to side effects; 2) approaching side effects and effectiveness as relational through comparison of medications and treatments; and 3) negotiating the limitations on choice that arise over time in the course of chronic illness. The analysis shows how side effects as lived phenomena are conceptualised through a complex set of relations involving effectiveness, anticipated side effects of other pharmaceuticals, and personal, situated histories of using (and not using) pharmaceuticals. I show that hormonal pharmaceuticals in chronic illness raise different questions about side effects than short-term use does. Hormonal treatments are experienced as invasive especially when they are felt to be moulding the body and mind over years. Side effects that might appear as tolerable during a fixed course of treatment may emerge as intolerable in long-term use of a medication.

My analysis should not be read as a critique of hormonal products, but as an investigation of the lived complexities of choosing between different constellations of pharmaceutical moulding of the body and mind. According to my research participants, hormonal products play a central part in endometriosis care, yet they often cause problems that appear disproportionate to their less-than-desired effectiveness. While living with hormonal products and their multitude of potential side effects, many of my participants hope that there will be other, non-hormonal pharmaceutical treatment options available in the future.

Hormonal pharmaceuticals and side effects

The article draws on science and technology studies (STS) approaches to pharmaceuticals as objects that are assembled through technological practices and political interests, and enacted as means of managing health and illness in situated practices of treatment and prevention (Dumit, 2012; Filipe, 2023; Johnson, 2017). Pharmaceuticals are material as well as social. As Cohen et al. note,

> recognizing that drugs are concrete material objects does not prevent their simultaneous analysis as complex social phenomena, embedded in the web of individual and collective meanings and interactions (Cohen et al., 2001: 450).

Likewise, hormonal compounds used in pharmaceuticals – for example, the synthetic progestogen known as progestin included in oral contraceptives – are historically shaped technoscientific entities that are understood to interact with biological processes (Oudshoorn, 1994; Roberts, 2007). Pharmaceuticals and hormonal compounds are also *lived* phenomena. In chronic illness such as endometriosis, pharmaceuticals are embedded in the daily routines of managing health and illness over years, even decades. My analysis highlights the temporality of endometriosis, as I trace how the effects of hormonal drug compounds are anticipated through past embodied experiences of pharmaceutical intervention.

All medications have some side effects – that is, effects that are not intended and are perceived as harmful or unpleasant. While possible side effects are typically expressed in numerical terms in drug safety information, side effects are not clear-cut or universal entities. For example, Fisher (2020) argues that adverse effects in clinical trials are enacted through situated practices of including and excluding participants or test results – practices that reinforce ideas of safety. After a pharmaceutical enters the market, and potential side effects are reported, the physiological mechanism underlying the undesired effect often remains unclear, and especially rare side effects may be contested (Oikkonen, 2022). As a result, some patient communities have built their own bodies of knowledge to prove the harm. For example, Gunnarsson and Wemrell (2023) analyse how a Swedish gynaecological health community engaged with different sources of information to argue that copper IUDs could have systemic side effects.

Some social scientists have focused on the range of effects that emerge in association with pharmaceuticals. Minna Ruckenstein (2019) reframes side effects as *life effects* to focus on the emerging entanglements of pharmaceuticals and humans. Examining mentions of antidepressants in the social media research database Medicine Radar, Ruckenstein notes that

> [a]rticulations of antidepressant encounters stress the instabilities of medicinal agents and call for their evaluation in light of the relations they form with contemporary health care arrangements (Ruckenstein, 2019: 8).

In Lisa Raeder's research on Swedish women's use of contraceptives, hormonal effects appear as ambivalent in that "hormones both engender and unsettle affective experiences of control over bodily processes and of selves" (Erikainen et al., 2025: 7). The lived effects of hormonal contraceptives are multiple, situated and often ambiguous.

In drug development and safety evaluation, the side effects of hormonal contraceptives have been compared to complications associated with pregnancy such as increase in the likelihood of blood clots (Bertotti et al., 2021; Kammen and Oudshoorn, 2002). Bertotti and colleagues (Bertotti et al., 2021) argue that this has resulted in the efficacy of a contraceptive product – its ability to provide secure contraception – being seen as safety, while the side effects of hormonal contraceptives have been trivialised. Kammen and Oudshoorn (2002) note that the development and evaluation of hormonal contraceptives has tended to focus on life-threatening side effects even when it is known that non-life-threatening side effects shaping, for example, moods or weight affect women's willingness to continue use. At the same time, side effects associated with contraceptives for men have been evaluated by different standards with low acceptance of side effects (Kammen and Oudshoorn, 2002; Oudshoorn, 2003).

A significant strand in social research on hormonal side effects focuses on life threatening complications (e.g., Geampana, 2019; Marks, 1999; Turrini, 2023). Less is known about how non-life-threatening side effects are conceptualised and lived with. Littlejohn and Kimport (2017) analyse how the uncertainty of side effects is communicated by clinicians in the US. According to their study, some clinicians juxtapose common desirable side effects (such as reduced bleeding) and less common undesirable side effects (such as irregular bleeding). At the same time, Littlejohn and Kimport note, clinicians make serious side effects (blood clotting) appear unlikely by highlighting the absence of individual risk factors. Likewise, Bertotti and Miner (2019) observe that many gynaecology textbooks frame contraceptive benefits as certain and risks as doubtful.

Studies focusing on women's willingness to use hormonal contraceptives have shown that women's views often differ from clinicians' or regulators' views. Littlejohn (2013) suggests that women find side effects related to mood or weight particularly difficult to tolerate as they run against gendered cultural expectations of being able to control one's moods and body. A historical study by Siegel Watkins (2011) on the implantable hormonal contraceptive device Norplant also highlights that side effects considered as insignificant by developers and clinicians, such as irregular menstruation, were experienced as highly problematic by the users. A recent study by Schneider-Kamp and Takhar (2023) documents that, with the rise of social media, side effects associated with combination oral contraceptive pills and perceived as affecting women's quality of life are seen as increasingly significant among young women.

Analytical framework and data

The article is situated at the intersection of social research on illness experiences and pharmaceuticals. While decisions about treatment involve many actors and practices, including clinicians' assessment of patients' responses to pharmaceutical compounds, the article purposely foregrounds the embodied experiences of people with endometriosis. This focus allows developing a nuanced understanding of how the embodied effects of different treatment options are felt and perceived. Focusing on hopes and concerns about possible effects also makes visible how past experiences with pharmaceuticals structure personal decisions whether to seek new medications and

how to act on clinicians' recommendations or peers' suggestions.

I approach choice of treatment as an issue that is situated, taking place within material and social constrains and in relation to other (always limited) options and scenarios. Annemarie Mol (2008) has distinguished between two organising rationales of patient participation, a *logic of choice* and a *logic of care*. According to Mol, the logic of choice structures the biotechnological market and posits patients as independent consumers who are expected to make choices that reflect their personal health goals. The logic of care, by contrast, centres on the complex webs of actors, technologies and practices involved in care that include (but are not limited to) patients. Unlike the logic of choice, the logic of care recognizes that care is an open-ended and nonlinear process. Yet, choice is not absent in care but, rather, a part of daily practices distributed across actors, technologies and interactions. Listening to patients' experiences is a precondition of care because the effects of technologies and treatments are always context-dependent: "If there are different treatments, the question is not just which of them is more effective, but also which effects are more desirable" (Mol, 2008: 54). Mol highlights that this is the case especially with chronic illnesses where 'health' as a desired goal is often unreachable and needs to be replaced by some other way of valuating effects (Mol, 2008: 54). Drawing on this framework, I approach the effects of medications in chronic illness as a matter of situated processes of valuation. I suggest that such processes are open-ended in the sense that individual bodies' responses to pharmaceuticals are ultimately unpredictable. It is also uncertain what the parameters are against which effects should be assessed, for example, how different types of side effects are to be measured and valuated – and by whom.

The materials analysed in the article were collected in Finland in 2021–2023 within an endometriosis subproject of a social science research project titled *Gendered Chronic Disease, Embodied Differences and Biomedical Knowledge* (GenDis). The materials included here consist of 16 semi-structured interviews I conducted with people living with endometriosis as well as 43 anonymous written stories of living with endometriosis in Finland collected through an online form on the project's website. Both the interviewees and those writing endometriosis stories responded to a call circulated on the project's social media channels and through a national patient organisation's networks. They lived in different parts of the country, were in their early 20s to late 40s, and had received treatment at different healthcare sites, including private gynaecologists, public endometriosis clinics, student healthcare and primary care at public health centres. Many had also visited emergency wards during acute pain attacks. As all the participants were fluent speakers of Finnish or Swedish – official national languages in Finland – further research is needed on the experiences of immigrants navigating endometriosis treatment within the Finnish healthcare system. Likewise, while the data allows an overview of experiences across the country, it does not provide insight on how pharmaceutical effects are navigated in a specific clinical setting.

The interviews covered a range of topics from first symptoms and diagnosis to experiences with hormonal treatments and other treatment options. I received written informed consent from all interview participants. The interviews have been transcribed verbatim and anonymised carefully. The written endometriosis stories were collected through an anonymous online form, which explained how the stories would be used in research and included information about how to withdraw a submission. The call for stories listed hormones as one of several themes that the writers could address. The stories ranged from a short paragraph to multiple pages. The collection and analysis of the interview and story data followed the ethical guidelines of the Finnish National Board on Research Integrity for research in the humanities and social sciences.

In analysing data, I identified ways in which the participants framed hormonal products as means of treating endometriosis and how they discussed the advantages and disadvantages of hormonal products. Among the interview participants, living without hormones by choice was not common, as the severity of endometriosis symptoms made it difficult. Only four interview participants had avoided hormonal products by choice for an extended period, and two of them had a relatively

mild case of endometriosis, which they acknowledged in the interview. In the endometriosis stories, all except two of the writers mentioned hormonal treatments, and many discussed both side effects and effectiveness. The interview and story data included participants who had experience of both hormonal medications and surgeries. Some of the surgeries were emergencies, treating endometriosis complications such as a ruptured intestine or ovarian cyst. Surgeries also included radical surgeries, in which the uterus and one or two ovaries are removed to treat a particularly aggressive case of endometriosis (see De La Hera-Lazaro et al., 2016).

The analysis focused on instances in which past embodied experiences of side effects were remembered and possible new side effects were anticipated. I traced how the participants conceptualised side-effects in relation to what they knew about other pharmaceuticals, often through their own or their peers' experiences. Building on the premise that pharmaceuticals are social and situated objects, I mapped the complex, evolving relations enacted between them in the data. I also identified ways in which the participants' considerations about which pharmaceuticals to use reflected concerns about healthcare infrastructures, such as the availability of a particular medication.

Establishing hormones as key medications while critiquing side effects

The views of hormones among the participants were complex. Many of them emphasised that hormonal products are key medications in endometriosis care yet also provided extensive critique of their shortcomings. The central role of hormonal products in alleviating endometriosis symptoms is present across the data. In many cases, the use of hormones had begun before diagnosis, when an oral contraceptive pill had been prescribed to alleviate period-related pain without examining what caused the pain. Many of the participants mentioned that when they had started a hormonal contraceptive recommended by a clinician, they had not fully understood how it could help reduce pain. One person mentioned that contraceptive pills had been "presented in the way that the alleviation of menstrual pain was a positive side effect of getting your contraception working" without explaining the link between pain and possible endometriosis (Interview, early 30s). For some others, it had been unclear why they would need the pill because there had been no need for contraception.

These examples illustrate that the ways in which the effects of hormonal pharmaceuticals are presented to people with suspected or possible endometriosis can be muddled and confusing. The participants described how such muddledness makes it difficult to arrive at sustainable, measured decisions about care. For example, pausing a hormonal product had resulted in the intensification or reappearance of pain in several cases. One participant reflected on the fact that she had discontinued her use of hormonal contraceptives in the years prior to her endometriosis diagnosis:

> If I had received the diagnosis earlier, perhaps it would have been wise not to discontinue the contraceptive pill. It's impossible to prove that it was because of that [decision], but it is likely that it played a role in that the illness progressed wildly (Interview, late 40s).

The delaying of diagnosis, or lack of adequate information about the connection between hormones, endometriosis and pain, had resulted in uninformed decisions about whether to use hormonal pharmaceuticals.

Descriptions of how discontinuing hormonal products had made endometriosis symptoms worse establish hormonal products as *necessary medications*. One participant explained:

> I lived about a year without any hormonal medication and the situation exploded. It [endometriosis] grew wildly. It got to the point that the pain was so severe that whenever I had my period my partner took me to the emergency room for an injection of pain medication (Interview, mid-30s).

Another participant described how, after 13 weeks off the pill, pain appeared:

> First intense ovulation pain, then strong pain during bleeding, after that pain during sex, then worsening defecation pain, unspecified pain around the rectum, and cramping that I could feel in the rectum and the lower abdomen as if someone was stabbing me' (Endometriosis story, early 20s).

After starting a new hormonal product, the pain situation improved. In these examples, using hormones appears as the foundation of endometriosis care. If there is an element of choice, it lies in the decisions about which hormonal pharmaceuticals to use.

In several interviews, the medical usefulness of hormones was framed in relation to a specific area of concern: future reproductive health. Reproduction was not a topic covered in the interview questions. Yet, several participants reflected on the effects of different endometriosis treatments on their fertility. They saw hormonal products as central not only for pain reduction but also for maintaining fertility in the future. This is based on the rationale that hormonal pharmaceuticals may prevent further damage to the reproductive organs. One interview participant in her late 20s explained this reasoning. She had experienced a range of side effects particularly impacting her moods. Yet, she continued using hormones because she saw them as "bad yet necessary in life" in order to "minimize the harm" to her reproductive capacity (Interview, late 20s). She elaborated:

> My view is that in a few years we'll try and see if we can have children, and if, possibly, we have children – I dream about two children – then after that I would stop the hormonal treatment entirely and would move to alternative [non-biomedical] treatments that I've been learning about (Interview, late 20s).

To her, hormonal products appeared as a rational choice in support of the long-term goal of having children. In this and several other interviews, the significance of biomedicine and hormonal treatment was acknowledged while a wish to live in a body that would feel less alien or chemically moulded was simultaneously articulated. Using a hormonal product was a choice that the participant had made in a particular moment in life, but a choice structured and curtailed by concerns about personal options in the future.

Reproduction structures endometriosis care also in another way: most hormonal products used to treat endometriosis are perceived by society to be primarily contraceptive tools. However, as the previous examples show, for people with endometriosis hormonal contraceptives may not be a means of preventing pregnancy but are perceived as a way of enabling it in the future. Despite this role of hormonal products in maintaining fertility, they are seldom recognised as medications by people unfamiliar with endometriosis. The participants provided extensive critique of this contraceptive framework, as in the following interview quote from a person who had experienced considerable side effects with all her hormonal medications:

> These experiments [with different hormonal medications] have been mentally tough and I would not have wanted them if it was just for contraception. I would have never done that but would have arranged contraception in another way. Also, many people with endometriosis don't even need contraception, are not in a relationship, or are not in a relationship with a man […] but they still need to use these treatments (Interview, early 30s).

Several participants expressed similar views emphasising that society needs to recognise both the medical necessity and the simultaneous inadequacy of hormonal pharmaceuticals in the treatment of endometriosis.

The sense of being failed by society and trapped in an impossible situation is further complicated by comparisons of side effects to the potentially devastating effects of endometriosis. One participant described how hormonal contraceptives had given her several side effects: "I lost a lot of hair, I gained several kilos, I got painful acne on my face and back and my depression got considerably worse" (Endometriosis story, mid-20s). After dropping all hormonal products, she first felt wonderful, "as if a foggy veil had been lifted from my head and for the first time in a long while I was able to feel something" but then the pain started: "It felt like my lower abdomen was on fire

and someone stabbed my uterus and squeezed it and stretched it" (Endometriosis story, mid-20s). This example articulates the sense of impossible yet necessary choice that many participants described when recounting their decisions about treatment. That the side effects of some hormonal medications may feel intolerable raises questions about what constitutes choice when living with a chronic, potentially progressing condition like endometriosis.

Approaching the effects of hormonal medications as relational

While not everyone has significant side effects from hormonal pharmaceuticals, those who do experience side effects need to navigate between products that are, in one way or another, unsatisfactory. Across the data, people with endometriosis drew comparisons between different side effects as well as between side effects and effectiveness. This involved charting pharmaceutical effects in relation to one's embodied experiences of past medications and symptoms. These were small, situated choices that were often reassessed by the person with endometriosis if the illness progressed or some side effect began to feel intolerable in the long term. This section examines how such choices between hormonal products are made.

The pros and cons of hormonal products were conceptualised in relation to other biomedical treatments. For example, using hormones was seen as a way of avoiding opioid-based pain medication or other medications experienced as addictive. Hormonal treatment was also viewed as a means of avoiding surgery and its potential long-term complications such as adhesions or nerve damage. Most often, however, the effects of a hormonal product were compared to other hormonal products. In the data, it was rare for a medicine to be seen as both fully effective and without any side-effects (though there were some accounts where it happened). Many participants described at length their experiences of trying to find a hormonal product that would be *effective enough* while also being *tolerable* in terms of side effects. Such comparisons of side effects and effectiveness situate medicines within a complex field of *relations* rather than along a straightforward continuum of better and worse treatments.

The decisions about what hormonal products to use included comparing different *types* of side effects. Many participants noted that side effects affecting mood, cognition or concentration were the most concerning ones. This is how one participant described her experiments with different hormones:

> With one pill I became raving mad. I felt so angry about small things – it reached the level where I wanted to throw things against the wall and I've never been that kind of person (Interview, late 20s).

Another person recalled: "With the hormone injections, I was awake for a month. I couldn't sleep at all, and I felt awful. I refused to continue that treatment" (Interview, mid-20s). Yet another participant explained why she considered her current, far-from-perfect medication the best one she had had:

> I've been awfully tired, and I have a constant headache, I also notice neurological effects, fast heartbeat or I tremble or feel weak. But it's not constant. It feels that I've been able to bear [the effects of] this one, but there appear to be only bad options (Interview, early 30s).

She considered her current side effects as manageable because they were less invasive than the ones caused by her previous medications.

Comparisons of side effects were complicated when further linked to effectiveness. Very often, the effectiveness of hormonal products was understood to range from ineffective to moderately effective – and occasionally sufficiently effective. Taking into consideration both side effects and effectiveness could be challenging, as in the following interview quote describing differences between hormonal medications:

> Either there have been serious side effects, or it has not been effective. Usually both. You take two [progestogen-only pills] a day and there's still bleeding. Then the doctors have said let's change the treatment and try something else. There has always been either side effects or there's no response, or both (Interview, mid-20s).

Choice appears here as a gradual process of trying out different options with no prior knowledge of what will work. It is a process that involves the patient's experiences as well as doctors' suggestions about when it is time to try "something else" and what that something else could be.

Clinicians specialising in endometriosis, such as gynaecologists at private clinics or public endometriosis units, take part in searching for a suitable medication. Many participants felt that general practitioners had few treatment options to offer. Doctors specialising in endometriosis, however, were seen as being aware that hormonal products may cause also uncommon effects. In one interview participant's experience, many endometriosis specialists acknowledged that "not all hormones are the same and not all hormones work the same way on different people" (Interview, early 40s). Several participants had found a specialist who listened to their experiences and concerns about medications. One person described her doctor's approach after several treatments had been ineffective: "The doctor said that it's okay, now we try different things until we find a suitable one that you can tolerate, a good treatment, we'll continue looking" (Interview, mid-30s). Participants who had had problems finding or accessing a trusted clinician called for a more patient-centred and personalised approach to treatment. For example, one interview participant noted that depression and mood changes were trivialised by some doctors. She suggested that discussing the different effects of hormonal medications with patients could help persuade those who consider giving up hormonal medications after first side effects:

> I would like there to be a culture centred on trying different options, so that a patient is listened to, and a doctor may say okay you don't want to use this product but how about if you try this other product, there are different products, they have different effects, and although you have had bad side effects four times, the fifth product could be the one that works and is acceptable in terms of its good and bad effects (Interview, mid 40s).

This example highlights the centrality of clinical encounters as sites where embodied experiences of pharmaceutical effects are acknowledged in assessing which effects are acceptable and which are too invasive.

When standard treatment options do not provide satisfactory treatment, clinicians specialising in endometriosis may engage in 'tinkering' (Mol et al., 2010) with medications. Many of the participants described how their doctors had suggested increasing dosages or combining two products. For example, some participants had been prescribed two progestogen pills a day instead of the usual one or had been offered a hormonal IUD and a progestogen pill to be used simultaneously. Such tinkering reflects the view that each body and each endometriosis responds differently to hormones. One interview participant, whose body did not respond to hormonal treatments in expected ways, described the process that led to her current treatment:

> In my case, combination contraceptive pills don't help with endometriosis, and it has always continued to spread despite the pills. Now, for the first time, I switched to a progestogen-only pill, and the pills are the first ones that have helped. Now a hormonal IUD has been added so that the endometrioma would dry [shrink] and the effect would be more localised. Another option would have been a double dose of the pills. It may sound extreme to a normal person that you have to take two pills a day, but you just get used to it (Interview, early 20s).

The process of trial and error also involves balancing patterns of effectiveness with side effects – both of which vary between people. Another participant described how her migraine aura, which constitutes a contraindication for the use of combination hormonal contraceptives, forced her to give up the vaginal ring, leading to a series of frustrating experiments with different side effects:

> While I used the vaginal ring, it didn't affect my moods, it didn't produce any adverse effects. But when I had to stop it and move to progestogen-only pills I got all the side effects. I'm now trying a fourth pill brand. I've also had different dosages of the pills. Now I have a prescription for a hormonal IUD, but I'm worried because you can't control it yourself. If it's inserted and then needs to be removed, a doctor is needed (Interview, late 20s).

The process of evaluating the effects of tailored combinations and dosages of medications in relation to side effects takes time. Not being able to react immediately to potential side effects, as in the case of the IUD, adds to the stressfulness of the process.

Many of the participants had learned to anticipate side effects and were prepared to situate the side effects and the effectiveness of new medications in relation to their personal histories of searching for treatment. One participant described having very little hope about finding a suitable product because all hormonal medications had worsened rather than alleviated her symptoms, increasing both bleeding and pain significantly: "When I started hormonal treatment the situation exploded. All hormonal treatments have provoked the endometriosis" (Interview, mid 20s). She continued: "I consider it nonsensical that treatment leads to the situation getting worse" (Interview, mid 20s). Concern about new medications appears as inevitable when previous experiences have consistently shown that one's body does not respond to hormonal medications in the way it is expected to. Yet, unexpected positive effects also exist. One participant described how, after years of living without hormonal medication because of previous experiences of side effects, she tried a hormonal IUD recommended by her gynaecologist: "During the first six months after it was inserted, I don't remember ever feeling as calm and in control as I did then" (Interview, early 40s). While the hormonal IUD provided relief that this participant did not anticipate, the effects of medications are seldom known in advance, which makes many hesitate whether they want to try a new medication.

Furthermore, evaluating the effects of hormonal products is not necessarily easy. While endometriosis tissue may show in imaging tests, side effects are not usually captured in the lab. Several participants noted that after years of living with endometriosis, they could not distinguish with certainty which symptoms were caused by medications, which by the illness, and which by other events and experiences in life. One interview participant pondered on the extent to which hormonal medications may have impacted her depression:

> it is impossible to see inside my brain and say that 30 percent of this is because of the hormonal medication and 70 percent is because of my childhood trauma or the stress caused by having endo (Interview, early 30s).

Another interview participant commented:

> You become blind to the use of hormones and their effects, perhaps because you have used them so long. It's not like when other people say "well, I quit the pills so now I'm my normal self again". I don't know if I'm my normal self because I have used [hormones] so long (Interview, early 20s).

In her case, hormonal medications had caused relatively few side effects, so the changes she described concerned the subtle ways in which hormonal products may mould the body and mind. The difficulty experienced by the participants reflects the scarcity of biomedical knowledge about long-term side effects of hormonal contraceptives (Bertotti et al., 2021; Kammen and Oudshoorn, 2002; Littlejohn and Kimport, 2017). At the same time, it highlights the central yet ambivalent role of embodied sensations as the means through which subtle changes in the body and mind can be perceived (Helosvuori and Oikkonen, 2024). The multiple effects of medication become blurry during long-term illness, making comparison of treatments challenging.

Negotiating the limitations on choice in the course of chronic illness

The passage of time shapes the parameters within which choices about hormonal medications are made in several ways. Comparisons between pharmaceutical side effects and effectiveness are complicated by how endometriosis as an illness often evolves over years. Likewise, the body that is being medicated changes with age. When a person with endometriosis finds a hormonal product that is sufficiently effective as well as tolerable, the situation might be short-lived. The following endometriosis story captures the range of changes that can take place over just a few years:

> When I turned 14, I had debilitating pain three weeks in a month. […] I started a contraceptive pill,

> which caused mood changes. After that I switched to another brand and that helped, I had six packets without a break. By the time I was 18, the pill didn't work anymore. […] It was replaced with another pill, which would have probably worked, but it caused serious self-harm symptoms. I got a [brand name] hormonal IUD. It worked for a year and a half keeping periods away. After that a [brand name] progestogen pill was added to the treatment. I'm currently treated with this combination and it's working so far. The IUD and the progestogen pill haven't caused significant side effects either. The IUD worsens my migraine, and I have acne, but these symptoms are more tolerable than endometriosis symptoms (Endometriosis story, early 20s).

Here the material relationship between a body, illness and hormonal treatments evolves within the scope of a few years – in this case, between the ages of 14 and 20. However, the participant did not know how long the current situation will last, as suggested by the uncertainty in the phrase "it's working so far".

The above example suggests that the tinkering involved in managing endometriosis treatment is an ongoing, open-ended process. The data includes numerous accounts of how a previously effective medicine no longer works, and new strategies of using pharmaceuticals need to be devised for the patient. Sometimes new side effects develop when a medication is used for a long period of time, for example, several participants had developed hormonal migraine, which they associated with hormonal medications – especially if the migraine disappeared when they paused the hormonal treatment. New side effects were anticipated with trepidation that affected everyday life and expectations about the future. This also applies to concerns about potentially declining effectiveness of medications. If a medication is now longer effective, the person with endometriosis is forced to make new choices about treatment, even when they may have hoped that no more choices are needed.

Several time-associated issues narrow down the parameters of choice. One is the onset of other health conditions. Most of the interview participants noted that they had at least one co-existing illness that complicated the treatment of endometriosis. Whether caused by endometriosis medication or developing independently, new diagnoses may impact the long-term use of hormones. For example, aura symptoms or high blood pressure limit the range of hormonal pharmaceuticals that can be used in endometriosis. Several participants described how they had to discontinue combination hormonal products because of a migraine aura and switch to a different type of hormonal product, such as a progestogen-only pill. Some had ended up with a product that was less effective or had more side effects than their original medication. In addition to migraine, depression and gastrointestinal conditions were mentioned numerous times in the interviews as complicating endometriosis treatment. As coexisting conditions needed to be taken into consideration when navigating the effects of hormonal products in the future, many participants described experiencing a sense of narrowing options.

The passage of time also complicates treatment in the sense that age as such is considered a contraindication for many hormonal products. The range of recommended hormonal products gets smaller when a person enters their late 30s, as some combination hormonal products are seen as too risky especially if a patient has other contraindications, such as elevated blood pressure or has gained weight. One participant elaborated on her experiences:

> There is the crisis of 40, which was clearly bigger for the doctors. It's as if when you turn 40 thrombosis will block your veins if you use combination contraceptives. It was somehow as if the risk was going to materialize immediately when you hit that particular age (Interview, early 40s).

A gynaecologist had told her that she would have to give up the combination hormone pills because she was 40 and overweight, which led to painful experiments with alternative products, most of which had significant side effects. The case highlights the discrepancy between endometriosis as a chronic illness and the reproductive framework within which hormonal medications operate (see also Oikkonen et al., 2025). However, the treatment needs of people with endometriosis are complex and evolving (Griffith, 2019; Hudson,

2020), extending beyond the logic of hormonal contraception designed for women in their twenties and thirties.

Across the data, a specific factor affecting the parameters of choice was the availability of pharmaceuticals. Problems with global supply chains are not new but they have increased in recent years, raising concerns in national and international healthcare bodies (Bogaert et al., 2015; Ferner et al., 2019; Scholz, 2020). Healthcare crises such as the Covid-19 pandemic and various national crisis have made visible the vulnerability of the pharmaceutical supply chains, which may rely on a few production facilities and specific ingredients produced in distant locations (Balfour, 2021; Wise, 2023). Hormonal contraceptives have been among affected pharmaceuticals. While not everyone who participated in this study had had supply problems, the issue was widely known among the participants, and many had peers who had been affected. One participant mentioned that some doctors considered drug shortages in treatment planning:

> When we have discussed options, a doctor has said that they don't recommend this one medication because there are supply problems. In that way it may narrow the options. Having to consider drug shortages when it anyway feels that the options are limited and not always good (Interview, early 30s).

Another participant explained that she was currently without a hormonal medication because her medicine was not available in pharmacies: "I have used a [brand name] progestogen-only pill since December, I have tried everything else and it's my last option. But now it's not available so I don't have any medication" (Interview, mid-30s). The participant felt that she was left with no choice because the other products she had used had had significant side effects.

Awareness of availability problems causes stress, structuring how people with endometriosis think about their future with hormonal products. One participant described how, after years of considerable side effects from numerous medications, she had finally found a "magic pill" that was both effective and without side effects. When I asked her about drug shortages, she told me the following story in which she situated her actions in the context of the Russian war against Ukraine, which had led to reports in the Finnish news media that Finnish pharmacies had sold out iodine tablets, widely known as a means of protecting the thyroid in case of possible nuclear fallout (see Valaskivi et al., 2019):

> Around the 24th [of February 2022] when Russia started the war against Ukraine, the only thing that I was thinking personally was not whether I should go and get iodine tablets but that I'll go and buy hormones for a year. Because there may be problems with availability, because you don't know how the situation will develop, I went and bought five packages of [brand name] (Interview, mid-40s).

While other people prioritised iodine tablets, her priority was to make sure she had access to the 'magic pill' that she felt had transformed her life. This story captures the deeply felt hopes and anxieties with which people with endometriosis have learned to approach hormonal medications. Like many other participants, she knew that hormonal medications that are effective and without side effects are rare and are therefore to be treasured.

The participants' views of acceptable side effects had also changed with age, affecting how they themselves enacted the parameters of choice. As shown in the first analysis section, some participants had become more accepting of hormonal products as they found out through experience the role of hormones in endometriosis care. Others, however, had grown more critical over years. Side effects that had been acceptable when they were younger appeared now as too invasive. One participant described how finally finding a suitable hormonal product with no significant side effects had made her realise how negatively the previous medications had affected her mental health:

> All my diagnoses of depression and such disappeared mysteriously. The same brain, a different hormone. I've also managed to lose 30 kilos while on [the new product]. I wish it had been on the market already 15 years ago. I also wish that I had been able to challenge [the previous treatments] because I feel that I've lost almost a decade with the mood symptoms and weight gain.

> […] The endometriosis was under control, it didn't spread, I didn't have pain, but what was the price? (Interview, mid-40s).

Finding a good hormonal product led to a re-evaluation of the side effects of all the previous ones. Another participant had a similar realisation after pausing her hormonal medication due to drug availability problems:

> I had wondered for four years why life was so hard with three children and I suddenly realised it was because of the progestogen pill that I had been taking. Everything was difficult, I was slow, and every task, like hanging the laundry, I had to tell myself that now you need to hang the laundry. But suddenly everything was easy and clear and there were colours in life (Interview, mid-30s).

She explained that the experience had taught her to be firmer when discussing hormonal medication options with doctors. She positions herself now as an active participant in the assessment of acceptable and unacceptable pharmaceutical effects. These examples demonstrate that finding a clinician who listens to a patient's experiences is pivotal to receiving good endometriosis care. Although endometriosis itself is not a contested illness, the side effects of hormonal medications often are contested, and the need to advocate for better medication in endometriosis resonates with social science literature on contested illnesses (Dumes, 2020; Richman and Jason, 2001).

Finally, some participants had begun to question the meaningfulness of the seemingly never-ending quest for a product that would be both effective and without side effects. This was especially the case when a person had experiences of severe and unpredictable side effects and anticipated that a new product could cause side effects that were worse than the current ones. One participant explained why she hesitated continuing the search for a more satisfactory product:

> I really don't feel I have the energy. It's like with antidepressants, you don't want to try many products because you may feel that it doesn't help. And I'm afraid of the side effects because I often get some (Interview, early 30s).

Another participant mentioned that her position had been to accept "the predictable awfulness" of endometriosis symptoms rather than to face the "unpredictability" of the effects of hormonal medications (Interview, early 40s). Experiences like these show that time may complicate rather than resolve the difficulties of choosing a hormonal treatment. With the accumulation of uncertainties and narrowing of options, the passage of time shapes how people with endometriosis wish and choose to live with hormones. Bodily effects and uncertainties that felt manageable at one point may emerge as unacceptable over years. At the same time, pharmaceutical effects that seemed unacceptable may appear as bearable because uncertainties that come with choice can feel increasingly stressful over time.

Conclusion

The article has explored how people with endometriosis negotiate pharmaceutical effects – both side effects and effectiveness – as they manage their endometriosis symptoms. Drawing on interviews and stories of living with endometriosis, I have shown that people with endometriosis approach the choice between hormonal medications as a complex, situated and evolving issue characterised by irresolvable tensions. The participants drew on their personal embodied experience as they engaged in continuous comparisons and reassessments of pharmaceutical effects in the course of their chronic illness. By focusing on the evolving complexities of choosing between less-than-ideal pharmaceutical effects, the article contributes to STS and social research on choice in medical care (e.g., Mol, 2008) and, in particular, in the use of hormonal contraceptives (Erikainen et al., 2025; Littlejohn and Kimport, 2017; Schneider-Kamp and Takhar, 2023; Siegel Watkins, 2011). Further research is needed on how pharmaceutical effects are negotiated in specific clinical settings of endometriosis care as well as on the experiences of specific patient groups, such as immigrants, navigating endometriosis treatment in Finland.

I have identified three issues that structure the views of pharmaceuticals in the interview and story data. Firstly, many of the participants main-

tained that hormonal pharmaceuticals should be seen as essential medications in endometriosis care while also arguing that they are currently insufficient medical tools that come with unacceptable side effects. This tension is visible in how people with endometriosis who wished to get pregnant in the future tolerated considerable side effects to maintain fertility. In these situations, using a hormonal product was perceived as a necessity and not a choice by people with endometriosis.

Secondly, I have traced how choice lies in the mundane, situated decisions about which hormonal medications to use. Choice involves drawing distinctions between different types and intensities of side effects and between side effects and effectiveness. Participants with endometriosis repeatedly reassessed which side effects were tolerable and what level of effectiveness was satisfactory, a process that involved compromise. Furthermore, gaps in biomedical knowledge about the causation of endometriosis as an illness (Hudson, 2022; see also Griffith, 2020; Seear, 2014) and about the side effects of hormonal pharmaceuticals (Kammen and Oudshoorn, 2002) distanced choice from the field of research-based knowledge and pinned it to embodied experiences. In the absence of biomedical data, the participants relied on their experiences of past side effects and effectiveness of different treatments. Side effects affecting the mind were experienced as particularly invasive and disturbing. While the critical literature on hormonal contraception addresses pharmaceutical effects on moods (Kammen and Oudshoorn, 2002; Littlejohn, 2013; Schneider-Kamp and Takhar, 2023), the stakes are different for people with endometriosis as non-hormonal products may not be an option, and hormonal products are used for years, often decades.

The analysis also highlights the centrality of clinical encounters in negotiating side effects and effectiveness. While the assessment of side effects relies on the embodied knowledge of the person with endometriosis, finding a clinician who recognises that bodies respond differently to hormonal medications, is pivotal. When standard hormonal treatment options do not work, specialist clinicians and their patients may engage in tinkering with dosages and combinations of pharmaceuticals to arrive at tailored treatment options. Such tinkering highlights the uniqueness of how each body and each illness responds to hormonal compounds. At the same time, the unpredictability of pharmaceutical effects forces people with endometriosis to repeatedly consider whether they are willing to try a new product with effects that cannot be known in advance.

Thirdly, the analysis has demonstrated how the parameters of choice narrow with the passage of time. Bodies' responses to hormone compounds change over years so that a previously suitable product may engender new side effects or become less effective. Age as well as the onset of new illnesses may rule out previously suitable treatment options. Availability problems affecting hormonal pharmaceuticals further curtail what kinds of choices a person with endometriosis will have. All these developments add to the stress and anxiety that many of the participants felt when navigating hormonal pharmaceuticals in a long-term, often progressing illness. The participants also described how their views of the effects of hormonal medications had changed over years. Some had reevaluated what side effects they considered acceptable. Others described how they found the seemingly never-ending search for medication through trial and error increasingly tiring. For them, choice involved trepidation about unpredictable new side effects that may be felt intensely across the body and mind. While previous literature has argued that attention needs to be paid to embodied experiences of pharmaceutical effects when hormonal pharmaceuticals are developed, tested and prescribed (Kammen and Oudshoorn, 2002; Littlejohn, 2013; Littlejohn and Kimport, 2017; Schneider-Kamp and Takhar, 2023; Siegel Watkins, 2011), my analysis has suggested that it is also important to recognise the evolving nature of embodied experience of pharmaceutical effects in chronic illness. How pharmaceutical effects are felt, how they are lived with and how they are valuated changes with age and the progression of illness.

The article has demonstrated the importance of foregrounding embodied experience in understanding the parameters within which people with chronic illness conceptualise and

make choices about pharmaceutical effects. While hormonal pharmaceuticals are often portrayed in biomedical discourse as a less invasive alternative to the invasiveness of surgery, my findings suggest that people with endometriosis experience many pharmaceutical effects as invasive, especially if they are perceived to be potentially permanent or to affect key aspects of personality. Focusing on experience also makes visible that choice is a complicated, evolving process that may follow a gradually narrowing path. When the process of trial and error results in a satisfactory treatment, choice can be experienced as empowering. Often, however, the open-endedness of the quest for a better medication can be exhausting. Yet, whether a new product is prescribed or an old one continued, having one's experiences of pharmaceutical effects acknowledged and being offered options appear crucial to good endometriosis care.

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