



UNIVERSITY OF GOTHENBURG

***“You have to be healthy
to cope with being sick”***

A qualitative interview study on the power relation
between the Swedish healthcare system and
endometriosis patients

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Aim: Analyse the power relations between the interviewed endometriosis patients and the Swedish healthcare system.

Theory: Power relations, power/knowledge, pastoral power, intersectionality and agency

Method: Qualitative interview study

Material: 20 semistructured interviews

Result: The results of this study showcase a psychologically draining situation where endometriosis patients are exposed to resistance, derision, prejudices and lack of knowledge within the Swedish healthcare system. To receive treatment and quality of life, the participants gained strategies and knowledge on their own to navigate the perplexing situation.

Abstract

Endometriosis is an inflammatory disease where cells similar to the uterine lining develop outside the uterus. It is estimated that every tenth person with a uterus has endometriosis. However, it is an unprioritised, unfunded and unresearched diagnosis since it only affects individuals assigned female at birth (As-Sanie et al., 2019). Women with chronic pain are generally perceived by healthcare personnel as hysterical, emotional, and complaining, and compared to men, receive less effective pain relief, less pain medication with opioids, more antidepressants, and more mental health referrals (Samulowitz et al., 2018).

With this in mind, this study aims to analyse the power relations between the interviewed endometriosis patients and the Swedish healthcare system through 20 qualitative interviews with participants aged 17-52. Two research questions were chosen to enable the analysis: How do the participants experience the Swedish healthcare personnel's reception of them as endometriosis patients? and What power do the participants have over the treatment of their endometriosis? The chosen theories are agency and an intersectional perspective on Foucault's theory on power relations, power/knowledge and pastoral power. The results of this study showcase a psychologically draining situation where endometriosis patients are exposed to resistance, derision, prejudices and lack of knowledge within the Swedish healthcare system. To receive treatment and quality of life, the participants gained strategies and knowledge on their own to navigate the perplexing situation.

Preface

My own first encounter with healthcare's power was twelve years ago. I sought medical care for symptoms of endometriosis and was sexually abused by a male general practitioner. In my attempt to tell others about what I experienced, they sided with the physician and tried to convince me that it was just a misunderstanding from my point of view. No one questioned his position of power against me, an 18-year-old in a vulnerable position seeking medical care.

“My story does not reflect everybody else's experiences but could encourage others to share theirs. A part of a researcher's work should be to search for and collect these stories, not just settle for their own. It should be construed instead as a sign that more people may have similar stories to tell.”

This was written by me at the beginning of my master's in 2022 while analysing my own experiences as an endometriosis patient in the Swedish healthcare system.

I dedicate this work to the endometriosis community, and I would like to thank the participants for their trust and for sharing their personal experiences. I could never have done this without you.

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1. Background

This chapter's first part, 1.1, briefly describes endometriosis and how the diagnosis is internationally underfunded and underresearched. The second part, 1.2, includes the thesis aim, research questions, and delimitations.

1.1 The Diagnosis of Endometriosis

“You are always inferior as a patient, but when you have something a bit diffuse, underresearched, and difficult to diagnose, that is also a woman's disease with a dash of 19th-century hysteria mixed in, it will never be easy.”

Quote from one of the participants in the study

Endometriosis is a chronic and inflammatory disease that is estrogen-dependent and thought to be caused by retrograded menstruations that cause cells similar to the endometrium to grow outside the uterine cavity (Nordengren, 2021). Every tenth person with a uterus is estimated to have endometriosis, which in Sweden corresponds to approximately 250,000 individuals (Nordengren, 2021). Endometriosis is one of Sweden's most common diseases, more common than diabetes and rheumatism (Andersson & Hägg, 2017).

Some common symptoms of endometriosis, listed by The Swedish Endometriosis Association (2021):

- Severe pain before or during menstruation and ovulation
- Prolonged and/or heavy periods
- Pain during urination, similar to a urinary tract infection
- Stool pain
- Pain during penetrative intercourse
- Lack of energy
- Body aches and fever
- Infertility

The diverse symptoms can mean that individuals with endometriosis meet many different healthcare professionals, as it takes an average of eight years to receive an endometriosis diagnosis in Sweden (Andersson & Hägg, 2017). A diagnosis is made by vaginal ultrasound or laparoscopy (keyhole surgery), and the average age when you receive your diagnosis in Sweden is 37 (Nordengren, 2021). The offered pharmaceutical treatment consists of hormone

therapy with various contraceptives, where the ambition is to lower the patient's estrogen levels (Nordengren, 2021).

The absence of reliable endometriosis care is not exclusively a Swedish phenomenon. Endometriosis remains internationally underfunded and underresearched, limiting the understanding of the disease and slowing much-needed innovation in diagnostic and treatment options due in part to the societal normalisation of women's pain and stigma around menstrual issues and the lack of disease awareness among healthcare personnel, patients, and the public (As-Sanie et al., 2019). Anna-Sofia Melin, a medicine doctor and specialist in gynaecology in Sweden, testifies about endometriosis patients getting accused of being delusional drug addicts who get referred to psychiatry and told that they are too sensitive and exaggerate their pain (Andersson & Hägg, 2017). The Swedish Parliament has repeatedly tabled motions to prioritise and improve Swedish endometriosis care but similar stories about the treatments continue to be raised over and over again (Motion 2014/15:2444; Motion 2017/18:1027; Motion 2017/18:1419; Motion 2017/18:3296; Motion 2018/19:2212; Motion 2019/20:94; Motion 2020/21:2463; Motion 2020/21:1913; Motion 2021/22:2254; Motion 2022/23:755; Motion 2023/24:2282). As-Sanie et al. (2019) disclose, societal factors such as clinical gender bias and inequities in the treatment of pain based on gender have been well documented and may contribute to the under-prioritisation of endometriosis research funding. Additionally, healthcare personnel may also not be knowledgeable about endometriosis and may, therefore, be quick to trivialise or assume patients are making up or exaggerating the severity of their symptoms.

Debates about endometriosis origin and treatment have been a hallmark of discourse about the disease. Despite continual medical debate about its aetiology, neither the theory of origin nor the treatment methods have changed significantly since it was first mentioned in 1921 (Nezhat et al., 2012). Jones (2015) argues that physicians have consistently linked endometriosis to women's deviations from the prescribed social norms of marriage and motherhood. Therefore, endometriosis is not merely a physical condition; it is also a cultural construction that informs beliefs about the relationship between women's reproductive anatomy and their social roles. Reminiscent of the wandering womb that roams throughout the female body searching for children that formed historical understandings of hysteria, endometriotic tissue is represented as roaming uterine lining in medical discourses, which suggests discourse about endometriosis is at least related to, if not influenced by the social

forces that shaped a diagnosis of hysteria (Jones, 2015). In this thesis, I, therefore, argue that endometriosis has taken up a diagnostic once occupied by hysteria, as both diagnoses pathologise not only specific physical symptoms but also social and cultural deviations from female gender norms that influence healthcare's perception and how they interact with the patients.

1.2 Aim and Research Questions

This study aims to analyse the power relations between the interviewed endometriosis patients and the Swedish healthcare system. In the field of Gender Studies, this study contributes to increased knowledge about a generally underresearched and unprioritised group that is systematically affected by the misogynistic history of the diagnosis of hysteria. The small amount of existing research is primarily carried out within medical faculties by healthcare professionals. Considering these previous studies, this study aims to bring an additional perspective by conducting a power analysis.

The following research questions have been formed to implement this:

- 1. How do the participants experience the Swedish healthcare personnel's reception of them as endometriosis patients?**
- 2. What power do the participants have over the treatment of their endometriosis?**

This thesis is limited to the Swedish healthcare system to provide an overview of how they interact with endometriosis patients. As the average time of receiving an endometriosis diagnosis in Sweden is eight years, and the symptoms are diverse, patients meet many different healthcare professionals within the system. Therefore, this study aspires to review all interactions with healthcare personnel, not just those with gynaecologists and doctors.

This thesis concerns subjects that are discussed in medical terms, where endometriosis is usually named from a biological perspective as a woman's disease, where a *woman* is interpreted from the concept of *sex* concerning anatomy, genes, and hormones. Thus, in this thesis, endometriosis is regarded as a disease that individuals with a uterus could be diagnosed with, where *gender* is a social construct regarding culture-bound conventions, roles, and behaviours that are expected of someone assigned *female* at birth.

2. Research Field Overview

This chapter collects earlier research that relates to this thesis. The first part, 2.1, is about how the historical diagnosis of hysteria impacts endometriosis. The second part, 2.2, touches on how a gender bias healthcare system affects patients with chronic pain. The third part, 2.3, overviews earlier qualitative studies about endometriosis patients' experience of healthcare interactions. The fourth part, 2.4, examines how physicians experience power within the doctor-patient relationship. Lastly, part 2.5 concerns an interview study on endometriosis patients' experience of power and knowledge within the Australian healthcare system.

2.1 The Historical Impact of Hysteria

“Some historical ideas are like viruses: over time, they mutate and adapt to changed circumstances. And while they may flourish more in some environments and certain periods than in others, they never totally vanish.”

Groneman (2000, p.181)

Throughout the years, there has been a medical obsession with the female reproductive anatomy. Pregnancy has been viewed as the completion of womanhood, while childlessness has been a synonym for failure or sickness (Johannisson, 2005). The discourse on hysteria and endometriosis both reflect sexist stereotypes about women by substituting the problematic womb for the ever-mystifying, unsolvable, enigmatic woman. Hysteria became synonymous with women, and it stood for “everything that men found irritating or irascible, mysterious or unmanageable, in the opposite sex” (Jones, 2015). Physicians found problems not with the symptoms and explanation of hysteria but rather with its patients. Hysteria became a “garbage can” diagnosis used to pathologise nonstandard expressions of femininity. Any aberrant behaviour could be a symptom of the disease; women were labelled hysteric if they either took feminine roles to the extreme or failed to adhere to the social expectations of women (Tasca et al., 2012; Jones, 2015; Nezhat et al.,2012).

Tasca et al. (2012). Jones (2015) and Nezhat et al. (2012) explain that the diagnosis of hysteria is the first mental disorder attributable to women, described in the second millennium BC. Over 4000 years of history, the treatments have included everything from herbs, sex, sexual abstinence, punishment, and purification through fire for its association

with sorcery and, most recently, clinically studied as a disease and treated with different therapies. Ancient Greek mythology spoke of the women's madness as derived from their uterus being poisoned by venomous fluids due to a lack of orgasms and "uterine melancholy". Thus arose the idea of female madness related to the lack of everyday sexual life: Plato argued that the uterus was sad when a man did not accompany it and did not give rise to a new birth. Aristotle, Hippocrates, and Galen agreed with the concept of sad wandering wombs; women were viewed as physically and theologically inferior beings, an idea that was rooted in the concept of male superiority, where a woman was referred to as a failed man. The concept of the wandering womb lived until Sigmund Freud (1865-1939) provided a contribution that led to the psychological theory of hysteria and the assertion of a "male hysteria". The diagnosis of hysteria was a significant form of neurotic illness in Western societies during the 19th Century and remained so until the Second World War. Then, there was a rapid decline in its frequency, and it has been replaced by the now common conditions of depressive and anxiety neuroses. Eventually, the concept of hysterical neurosis was removed with the 1980 Diagnostic and Statistical Manual of Mental Disorders 3 - DSM-III (Tasca et al., 2012; Jones, 2015; Nezhat et al., 2012).

2.2 A Gender Bias Healthcare System

As-Sanie et al. (2019) disclose that, societal factors such as clinical gender bias and inequities in the treatment of pain based on gender may contribute to the under-prioritisation of endometriosis. Samulowitz et al.'s (2018) literature analysis show that gender norms are reflected in health care, where they can be held by patients, researchers, and physicians and can lead to gender bias and medically unmotivated differences in the treatment of men and women. Chronic pain is a field within medicine and healthcare that is significantly affected by gender bias. In Swedish primary healthcare, 20–40 percent of all consultations are occupied by patients with chronic pain (Samulowitz et al., 2018).

Samulowitz et al. (2018) continue by remarking that evidence-based medicine is a cornerstone of healthcare and that medical professionals' decisions should be based on current evidence. However, Samulowitz et al. (2018) show that men are used as a basis for treating both men and women. This is called gender blindness, which is the fact that a great deal of medical knowledge is based on research performed on men. Regarding pain patients, Samulowitz et al. (2018) show that masculine attributes like strength, endurance, and

stoicism are highly valued and seen as the norm within healthcare compared to feminine characteristics like sensitivity and expressed discomfort.

The consequences of certain conditions prioritising or down-prioritising in research and healthcare may also be reflected in status hierarchies of diagnoses (Samulowitz et al., 2018). In medical articles, women are pictured as more sensitive to pain and more willing to report pain than men. The phrase “*be careful*” is more given to women as advice, while “*pain goes with heavy work*” is more often given to men. Some of Samulowitz et al. (2018) analysed articles also show how women, to a greater degree than men, were viewed to be accustomed to internal pain because of menstruation and childbirth. This was connected to the presumption that women have greater body awareness, while others suggested that pain without an external cause is viewed as a natural characteristic of women’s bodies. Samulowitz et al. (2018) also show, like Jones (2015), that women with pain are often perceived as hysterical, emotional, complaining, not wanting to get better, and as malingerers who fabricate their pain. Their pain was more assigned as psychological rather than somatic. Women’s narratives about their experiences with healthcare showed how hard they have had to work to be taken seriously, believed in, and understood in their medical encounters. The encounters between the woman with chronic pain and her physician were described as a struggle for both the patient and the physician (Samulowitz et al., 2018).

Samulowitz et al. (2018) also show that women with chronic pain are judged by their physicians based on how they look. Women were mistrusted when they looked too good, as in “*you can’t be sick,*” or judged as unreliable if they did not look good enough. Statements like “*You don’t look ill*”, “*You always look so healthy!*” or “*You are so young!*”. Those statements indicated little understanding of how much pain they had. Gender bias was also shown in prescribed medical treatments. In these studies, different medical needs could not explain the differences in treating men and women. Women, compared to men, received less effective pain relief, less pain medication with opioids, more antidepressants, and more mental health referrals. Samulowitz et al. (2018) confirm a paradox: It is more acceptable for women to show pain, and more women receive diagnoses linked to chronic pain. However, women’s pain is taken less seriously, their pain gets discounted as being psychological or nonexistent, and their received medication is less adequate than the treatment given to men.

2.3 Endometriosis Patients' Perception of Their Encounters with Healthcare

Grundström et al. (2018) conducted a qualitative interview study that analysed the experience of healthcare encounters among twelve Swedish individuals with endometriosis. The interviewees felt very vulnerable and alone due to being disbelieved by healthcare personnel, as they were perceived to be weak and exaggerating or imagining their symptoms. They expressed that healthcare personnel were focused on finding “*easy explanations*”, which were, for example, infections, miscarriage, or irritable bowel syndrome (IBS). When the symptoms did not disappear, the healthcare personnel resorted to normalising and trivialising the symptoms, which made the interviewees feel like they were not interested in understanding them. Some of the interviewees testified about personnel who sighed, tapped their fingers on the table, avoiding eye contact, and used a medical discourse that was incomprehensible to them. They also expressed that they felt dependent on the healthcare personnel's competence while experiencing that they lacked basic knowledge about endometriosis. The ignorance they met made some interviewees feel apathetic and gave them a sense of hopelessness.

Grundström et al. (2020) conducted another qualitative study, this time based on sixteen blog posts written about Swedish healthcare encounters by individuals diagnosed with endometriosis. These results further demonstrate that the journey through healthcare was experienced as a prolonged struggle, including normalisation, trivialisation, and distrust. Several of the blog posts were stories of healthcare personnel not wanting to prescribe painkillers or where the bloggers felt that they had to beg to get proper pain relief. Some bloggers had been told that they were imagining or overstating their pain and that they were too young to be as sick as they were. Some healthcare personnel went so far as to call them drug addicts, which was perceived as offensive and degrading by the bloggers. They also described encounters with healthcare personnel who expressed pain to be physically harmless and severe period cramps as something “normal”. Some bloggers also expressed being misdiagnosed with several different disorders, such as anxiety, IBS, premenstrual syndrome, or sexually transmitted diseases. The negative response and disbelief from healthcare personnel were described as resulting in low self-esteem, low self-confidence, and feelings of anxiety, resignation, and despair. Several bloggers felt violated and frustrated by healthcare

personnel who claimed to be experts but showed a lack of competence by asking inadequate questions or conveying inaccurate information.

In both articles (Grundström et al., 2018; 2020), the participants describe the importance of acknowledging their frustration and pain, which makes them feel valid, visible, and sane. Not being acknowledged throughout many years and being subjected to destructive encounters negatively affected the participants' thoughts and perceptions about themselves and their bodies. Being seen as an individual, not a body or object, was critical to a positive healthcare experience.

Participants in Grundström et al. (2018; 2020) expressed that some healthcare providers advised them to get pregnant, as they told them that it would help them with their endometriosis symptoms, and in some cases, they were even promised that pregnancy would cure their endometriosis. Some participants found pregnancy as a treatment method confusing as they had previously been told by other healthcare personnel that they could not get pregnant because of endometriosis. The advice to get pregnant felt intrusive to some of the participants as they were not happy that healthcare personnel tried to influence such an important life decision.

International qualitative studies from Hungary, Netherlands, South Korea, Great Britain, Mauritius, Australia, USA, Canada, and Italy all demonstrate similar narratives of problematic and insufficient healthcare as the Swedish ones (Chan Sun, et al., 2022; Denny et al., 2018; Grogan et al., 2018; Ilschner et al., 2022; Le Roux et al., 2022; Márki et al., 2022; Metzemaekers et al., 2021; Moradi et al., 2014; Rea et al., 2020; Rowe et al., 2021; Wren & Mercer, 2022; Yoon et al., 2021; Young et al., 2016; Young, et al., 2020; Zale, et al., 2020). However, in countries where healthcare is not state-funded, there is the aspect of the cost of healthcare, which reinforces the social power divide between physician and patient even more (Young et al., 2020). A study across Europe and America concluded that the average annual total cost of healthcare for an endometriosis patient is 3113 € (\approx 35 000 SEK). According to the results, the healthcare costs were mainly due to surgery (29%), monitoring tests (19%), hospitalisation (18%), and physician visits (16%) (Simoens et al., 2014). Therefore, it also becomes a question of who actually can afford to seek care for their symptoms, which could be one of the reasons why physicians used to wrongfully reference

endometriosis as a “*career woman's disease*” since they were the only ones who could afford to seek medical care for their symptoms (Jones, 2015).

Earlier mentioned qualitative studies on endometriosis are generally conducted within medical faculties. However, this year, Ina Hallström, PhD in Gender Studies at Stockholm University, published her first article about her work on endometriosis. In this article, she describes the relation between time and gender in living with endometriosis, and she titles this concept *endo time*. She explains how she identified three prominent stages of *endo time* in the interviews' narratives. These were *waiting time*, *cyclical or chronic time*, and *sedimented time*. The *waiting time* is identified as the long time people with endometriosis have to wait for a diagnosis and the detrimental effect this has on the person. *Cyclical or chronic time* is recognised as the cyclical symptoms experienced by a person with endometriosis are *normalised*, while chronic symptoms are *stigmatised* by healthcare and society in general. Lastly, *sedimented time* is identified as when different strategies due to symptoms of endometriosis sediment into embodied habits (Hallström, 2024).

2.4 Physicians' Perception of Power in the Doctor-Patient Relationship

“I’ve learned very early on that the relationship between a doctor and a patient is unequal. You are in a position of power as the doctor. As much as you may try to minimise that, the actual reality is that they have you, in general of course, have you on a pedestal. You have to be respectful of that differential nature of the relationship”.

Quote from a physician in Nimmon and Stenfors-Hayes (2016, p. 4-5)

To provide equal patient care, healthcare personnel must consider the social relations connected with power relations and how they act and handle interpersonal encounters. In a healthcare encounter, the physician is influenced by whom they meet, which means that through perceptions, ideas, norms, and values, they create assumptions and use categorisations to understand and act with others through examples like class, gender, and ethnicity. The healthcare personnel has a responsibility to be able to recognise, problematise and analyse their own hierarchical power and always have a critical approach to social categorisation in their encounter with patients to be able to treat them fairly, regardless of

whether the patient is a man, woman, or identifies as neither, young or old, low-educated or highly-educated, whether religious or not, whether the person needs an interpreter, and so on (Lill & Råmgård, 2016).

Nimmon and Stenfors-Hayes (2016) interviewed thirty physicians about their perceptions of power in the doctor-patient relationship. Their responses were divided into three categories depending on their perceptions. The quote at the beginning of the paragraph is placed in the first category of responses: the physicians who perceived themselves to hold power in doctor-patient encounters. The physicians in this category reflected on the presence of power extensively by describing how the power dynamic in a doctor-patient interaction was uneven. Because of their medical training and credentials, they were in a position of power in the doctor-patient encounter. They described how it was their ethical responsibility to be cognizant of the effects of power in their relationship with patients and to not take advantage of their position of power. They expressed that their position of power needs to be acknowledged by physicians and that they have a responsibility to act in the patient's best interest by "*managing*" their position with integrity. These responses connect to Lill and Råmgårds (2016) description of sensible healthcare personnel. Nimmon and Stenfors-Hayes's (2016) second category of responses showcased physicians describing doctor-patient encounters as a struggle where the physicians perceived their power was waning in the doctor-patient relationship. They expressed that their power is diminishing in the context of a changing healthcare culture that encourages patient rights, patients as consumers of healthcare, and well-informed patients. They described how tensions emerge when patients make unreasonable demands on the physician. One physician even said their patients were bullies because they were "*unreasonably demanding*". The third category of responses highlighted how physicians perceive power dynamics as non-existent or irrelevant in doctor-patient interactions. Some of the physicians in this group perceived an absence of power. Others describe how they were on a level playing field with their patients and how power dissolves through a balanced, empowering doctor-patient power relationship (Nimmon & Stenfors-Hayes, 2016).

2.5 Endometriosis Patients' Perception of Power in the Doctor-Patient Relationship

Young et al. (2020) conducted a qualitative interview with 26 participants diagnosed with endometriosis about how they navigated power and knowledge within the Australian healthcare system to receive healthcare that assists them in managing their endometriosis. The participants revealed the challenges they faced, such as physicians' lack of knowledge regarding endometriosis and their attempts to normalise the patient's pain and discomfort. Despite their perceived expertise, physicians (often gynaecologists) were seen by the participants as an authority with *“the power of your life”* and *“the power of your quality of life”*. Some of the participants had their physicians reprimanded when they had caused them physical or emotional harm. They also shared these experiences with other individuals with endometriosis in the hope that they would not need to suffer from the same arrogance. Other participants did not complain to authorities because they experienced it as *“your word against theirs, and who are they going to believe? A patient or a doctor?”*.

Focusing on the participants' perception of their own power and knowledge in the context of their endometriosis, some expressed, *“I know my body”*. The physicians were, however, reported as favouring their own perspective despite the patient's efforts to convince them of the validity of their knowledge about their bodies. When this happened, some participants expressed that the physicians made them start to doubt themselves knowing their bodies when experiencing symptoms that a physician would not treat. It was, therefore, not unusual for the participants to express that *“you have to be your own doctor”* for endometriosis, given the limitations of the healthcare they received. Several participants concluded that they had endometriosis themselves and thereafter suggested the diagnosis to a gynaecologist. They expressed that they came to believe they had endometriosis based on information encountered in their medical journals, on the internet, from support groups for IVF and endometriosis, or from friends and family. However, they reported that the gynaecologists often were unwilling to diagnose endometriosis if they made the initial suggestion that it could be endometriosis. They also expressed frustration in having to change doctors several times to find one that could assist in managing their endometriosis. Many of the participants spoke of self-advocacy as a crucial and necessary part of having endometriosis to ensure their needs were met (Young et al., 2020).

3. Theoretical Framework

This chapter presents the theories central to implementing the analysis of the results. The first part, 3.1, introduces a Foucauldian perspective on power relations, power/knowledge, and pastoral power while adding an intersectional perspective. The last part, 3.2, is about agency.

3.1 A Foucauldian Perspective on Power Relations

A central part of this thesis is that the power relation between endometriosis patients and the Swedish healthcare system is shaped by obsolete and misogynistic institutional values linked to the historical diagnosis of hysteria. In the first volume of *The History of Sexuality*, Michel Foucault refers to the hysterisation of women as an outlet for the repressive techniques of power that reinforce the image of women as irrational, unpredictable, emotional and unreliable (Johannisson, 2005). Using a Foucauldian perspective on power when reviewing healthcare experiences affected by these obsolete and misogynistic institutional values aims to explain the multiple functions of power, how power is exercised and its effects. It enables us to review how the relationship affects the endometriosis patients and how knowledge becomes an effect of power.

Foucault never created a method of analysis; he called his methodological approaches “gadgets” and encouraged researchers to use them as “thinking tools” (Jackson & Mazzei, 2012, p. 54). Focusing solely on “*who exercises power over whom*” can be a limited investigation. Instead, Foucault asks questions such as: “*If power is exercised, what sort of exercise does it involve? In what does it consist? What is its mechanism? How does it happen?*” (Jackson & Mazzei, 2012, p. 55). These questions have been used as “thinking tools” to analyse different power exercises in the collected material (both by healthcare providers and endometriosis patients) and how they ultimately affect patients' perceptions of their healthcare experiences.

The general perception of a doctor-patient relationship is that the doctor possesses the overall power. Foucault critiques this idea of power as a possession and the concept that those who “possess” power control and wield power over subjects with no agency. According to Foucault, the view of intentional power is limiting because it enables homogenising subjects as having universal characteristics. Foucault's theory implies that power reaches every corner

of individuals and inserts itself into their actions, attitudes, discourses, learning processes, and everyday lives. He acknowledged that power could exist in unequal relations and that these relations produce effects inscribed into the entire power network. Power is a chain that relies on relations to advance, multiply, and branch out deeply into social networks (Jackson & Mazzei, 2012). This Foucauldian perspective of power enables one to analyse the participants' experiences in this thesis further than just viewing them as powerless victims of the Swedish healthcare system.

The healthcare system is built upon medical science, which society accepts as the truth. Foucault (1971, p. 6) insinuates that the one who has power does have the truth, that truth is produced by power, and that truth is not outside of power. The formation of knowledge occurs within relations of power, and power produces knowledge. Using this perspective of knowledge clarifies that the healthcare system's truth is formed by its power. The participants in this thesis oppose the societal perception of healthcare power/knowledge, which could be theorised through Foucault's perspective on *savoir* and *connaissance* knowledge (Jackson & Mazzei, 2012). *Connaissance* is didactic, received knowledge, like family values and described in part 5.1 as the initial trust participants had for the healthcare system before they experienced repeated rejections. *Savoir* is what Foucault expresses as constructed knowledge produced through experience and relations with others, and *savoir* defines and changes how a subject participates in the world. This constructed knowledge is described in part 5.1, where the participant's trust in the Swedish healthcare system changes because of their experiences of the reception they get as endometriosis patients.

During the interviews, a recurring aspect of participants disciplining themselves to receive treatment became apparent and is described in parts 5.2 and 5.3. These experiences could be comprehended from the concept of pastoral power that Foucault introduced as a disciplinary individualising form of power. The idea was developed from a Christian perspective, where priests directed their power towards the care of members of their congregation. The pastor's role was that they were responsible for each group member, and everyone had to submit themselves to the pastor. The pastor knows the group and encourages them to work on their salvation and preparation for eternal life. Foucault believed that pastoral power remained in modern society and that instead of priests, it is exercised, for example, by doctors (Jones, 2018). This power is exercised by disciplining patients through clinical categorisation and surveillance and using contemporary health policies to encourage patients to make more

appropriate lifestyle choices and care for themselves (Waring & Latif, 2018). Foucault references that hysterisation was consequently a way of disciplining women to fit into their functions in the reproductive sphere. As a disciplinary measure, the hysterisation allowed for a comprehensive pathologising of women who deviated from normative femininity (Johannisson, 2005). Young (2003) describes how pastoral power only appears to be gentle and benevolent to the pastor and the one affected by it. It is interpreted as an act of protection, where you are expected to comply and not question it. She compares the aspect of pastoral power to how men practice violence as protection and for their own gain. This aspect can be seen in the participant's narratives in part 5.5, where the physicians blame the patients by presenting arguments that could be compared to *"you decide for yourself, but there is a right and a wrong choice"*.

3.1.1 Intersectionality

"Not only gender and sex, but also other categories of identity such as race, ethnicity, age, class, weight and ability influence how pain is seen and treated."

Folkmarson Käll (2012, p.4)

Folkmarson Käll (2012) establishes that pain is, in many ways, a gendered experience and how pain is conceptualised, lived, diagnosed and treated cannot be divorced from structures of power. This gendered experience also becomes apparent in the interviews of this thesis, based on the aspects of age, weight, appearance, and behaviour as grounds for receiving worse reception from healthcare personnel, which are presented further in the results in parts 5.2, 5.3 and 5.5. To be able to apply Foucault's "thinking tools" thoroughly, we will add an intersectional perspective to this thesis and use it as an analytical perspective on how several orders of power could affect endometriosis patients with more grounds (than being an individual assigned female at birth with symptoms of endometriosis) could affect their chances of receiving reliable care.

The term intersectionality was introduced into feminist studies by professor Kimberlé Crenshaw (1991) to visualise how we often do not understand or recognise the discrimination or marginalisation that individuals are exposed to if they are seen as, or identify with more grounds that could make them vulnerable to discrimination than just one. Her concept of intersectionality comes from the understanding of how black women's experiences could not be analysed appropriately based on belonging to the category of a woman or being racialised

as black. However, intersectionality can be implemented in all socially and culturally constructed categories based on oppressive power relations (Crenshaw, 1991).

The results in part 5.3, where age, or rather the lack of age, are presented, will be discussed as an intersectional perspective to why the patients are not offered treatment or are getting a bad reception from the healthcare personnel. This discussion will be based on the perspective that the hegemonic discourse on childhood influences children's subordination in age-based power arrangements. Children's rights in society are overlooked as being different from the norms of adults. They are considered “not-yets” and are not taken seriously regarding their childhood identity (Moosa-Mitha, 2005). Adults, or individuals assigned male at birth, are considered the norm within the healthcare system and medical science (Samulowitz et al., 2018). Therefore, I intend to theorise how this becomes a mechanism in the experiences of teenagers with endometriosis in the Swedish healthcare system.

3.2 Agency

Young et al. (2020), Grundström et al. (2018) and Grundström et al. (2020) studies show how endometriosis patients feel that they need to treat their symptoms of endometriosis themselves since they do not receive enough (or any) treatment from healthcare. Several also testified about informing unknowing physicians about endometriosis and compared themselves to partners instead of patients (Young et al., 2020). Experiences like these were also described by the participants in this study, which are further discussed in the results in parts 5.6 and 5.7. This study, therefore, intends to theorise the participants' experiences through agency as their relations of subordination to healthcare forms individuals Foucault (1991) describes as people who can decide, choose, and navigate their lives. I will, however, not only have a Foucauldian approach to agency. I will use a miscellaneous understanding of how and why agency could develop within an individual with the experiences of being an endometriosis patient within the Swedish healthcare system. My interpretation is that I do not want to be restricted to just one concept of agency.

From Foucault's (1991) perspective, I relate that agency alludes to individuals' thoughts, feelings, and actions that express their power. Individuals' cognitive beliefs are shaped by their experience, their perception of the social system, their environment, the status they are born into, and their social network. This notion could explain why and how the participants

act in their medical appointments. In part 5.7, I have used Judith Butler's (2002) perspective, which shows how participants, through repetition of rejection, conclude that they must treat the symptoms of their endometriosis on their own. Butler interprets this as the formation of agency, which occurs in and through the moment of repetition of an act since they oppose the existence of an individual possessing agency as they do not believe the “self” to be a reality but rather a social construct. From Mahmoods' (2005) perspective on agency, I have chosen to use the aspect where she suggests viewing the formation of agency as a capacity for action that historically specific relations of subordination enable and create. This perspective alludes to how agency could be formed among endometriosis patients who have had enough of healthcare discrimination that is tainted by obsolete and misogynistic institutional values linked to the diagnosis of hysteria.

4. Method and Material

This chapter describes how the study was conducted. The first part, 4.1, discusses the application of the method. The second part, 4.2, explains how I approached selecting participants and ethical considerations. The third part, 4.3, discusses the analysis of material, and the last part, 4.4, discusses reflexivity and source criticism.

4.1 Application of Method

The chosen method is qualitative interviews to answer the study's research questions and to enable the participants to express opinions and viewpoints in their own words. The qualitative research interview seeks to understand the world from the interviewee's point of view and develop the meaning of people's experiences. It aims to obtain descriptions of the interviewee's view of life and interpret the meaning of the described phenomena (Kvale & Torhell, 1997).

In search of participants, I uploaded the interview request (Attachment 1.) on my social media platforms (Instagram, Facebook, and LinkedIn) at the end of January. I encouraged my social surroundings to share it on their platforms. A few days later, I was notified that the doctor Anna-Sofia Melin, also known as @endometriosdoktorn, had shared my interview request on her Instagram story with her 10 400 followers. Anna-Sofia Melin has notably high ethos in the endometriosis community as she is viewed as one of the most prominent specialist on endometriosis in Sweden while also openly criticising the absence of reliable endometriosis care. By sharing my interview request with her followers, she increased the study's credibility as she endorsed it. By doing so, she also shows that she believes this is a relevant study in the field. The response after she shared the request was beyond my expectations as many possible participants started to reach out to me, also by some who just wanted to praise the importance of the choice of the study subject. Since most participants found the study on Anna-Sofia Melin's Instagram story, one must question how that could affect the collected interview material. It could mean that these participants are more up-to-date and involved in the discussion surrounding the absence of reliable endometriosis healthcare than others who do not follow her content about the newest research related to endometriosis. They may have critically analysed their own experiences more before based on reading the results of other studies. Nevertheless, one could not state that this is not the

reality of the other participants who do not follow her, as they could have done so too, as it is a common experience for an endometriosis patient to feel the need to do much reading yourself as knowledge is absent in healthcare (Young et al., 2020; Grundström et al. 2018 and Grundström et al. 2020).

Twenty interviews were conducted, recorded, and manually transcribed during February 2024. All of the interviews and transcriptions were done in Swedish. Three interviews took place face-to-face; the other seventeen were conducted through Teams or Zoom, depending on what the participants preferred. A semi-structured interview basis (Attachment 2.) was used, and the interviews differed between 18 and 56 minutes. Names of participants, healthcare personnel, locations, and clinics were anonymised during the transcribing of the interviews. After the transcription was finished, the interview recording was deleted.

4.2 The Participants

It takes an average of eight years to receive an endometriosis diagnosis in Sweden (Andersson & Hägg, 2017), and the average age for receiving your diagnosis is 37 years (Nordengren, 2021). I therefore wanted to include those who have not yet received their diagnosis (or might never get one), as the patient or the physicians may not want to carry out a laparoscopy. Also, you do not have to have a diagnosis to experience power relations in connection with endometriosis healthcare; many appointments and interactions with healthcare personnel occur before receiving a diagnosis. However, earlier studies have mainly welcomed participants with established diagnoses, not those who have suspected endometriosis (Grundström et al., 2018; Chan Sun et al., 2022; Denny et al., 2018; Grogan et al., 2018; Ilschner et al., 2022; Le Roux et al., 2022; Márki et al., 2022; Metzemaekers et al., 2021; Moradi et al., 2014; Rea et al., 2020; Rowe et al., 2021; Wren & Mercer, 2022; Yoon et al., 2021; Young et al., 2016; Young et al., 2020; Zale et al., 2020). This study thus welcomed participants who already had a diagnosis but also those who did not; four of the twenty interviewed women had not got a confirmed diagnosis yet. These other qualitative studies also mainly interviewed participants described as being in their “fertile age”; endometriosis is a lifelong disease, as adhesions do not just simply disappear because you enter menopause. Therefore, this study welcomed everyone, regardless of their age, and I was also interested in knowing if their age could be relevant to their experiences. Thus, the participant's current age and a given figurative name will be presented in the results. The participants were

predominantly white, heterosexual, cisgender women aged between 17 and 52 years, with a wide age variety.

4.2.1 Ethical Considerations

Since the absence of reliable endometriosis care is not exclusively a local phenomenon, this study welcomed voluntary participation from all over Sweden, as I used the option of digital interviews. The participants were informed in the Interview request (Attachment. 1) and at the beginning of the interview that their names and locations would be anonymised. I have chosen to anonymise everyone's location as I consider it irrelevant to the results. I value the participants' identities as being completely anonymous, and I do not wish for any healthcare institution to be able to identify a patient. There was a wide range of locations for the participants, but the study would have had to be bigger and have more participants to locate geographical differences in the material. However, as mentioned before, the lack of geographical distinctions could also indicate that the narratives are similar, as the experiences from the absence of reliable endometriosis are not a local phenomenon.

In the Interview request (Attachment 1) and during the interviews, I informed the participants that they could withdraw from the study without questions if they would have liked to. I asked permission to record the interviews and told them that the recording would be deleted after the transcribing was finished and that unauthorised persons would not handle the transcriptions. The participants were informed that they would be sent the completed thesis and that it would be published in Gothenburg University's database.

I was transparent about my own experience as an endometriosis patient, as I wanted them to know that I understand that it could be physically draining to talk about this subject but also so that they would see that I had an insight into the system.

4.3 Analysis Method

Thematic content analysis was used to analyse the 96 pages of transcribed interview material. The method is used to portray the thematic content of interview transcripts by identifying common themes in the texts provided for analysis. Anderson (2007) describes it as the most foundational method of qualitative analytic procedures. While transcribing the interviews, I started by colour-marking positive and negative experiences with healthcare personnel as the

first categories. Then, bold-marking experiences that notably stood out and underlined those similar to the experiences of other participants. After the transcriptions, I reduced the material to 30 pages of extracted quotes. I created subcategories based on the eight distinguished subcategories, which is also how I have chosen to present my results in Chapter 5:

- 5.1 The Reception of Endometriosis Patients
- 5.2 How Appearance and Behavior Affect Reception
- 5.3 Being a Teenager with Endometriosis Symptoms
- 5.4 Lack of Knowledge
- 5.5 Placing the Responsibility on the Patient
- 5.6 Not Being Included in Your Treatment
- 5.7 Becoming Your Own Specialist
- 5.8 The Lottery of Receiving Good Care

The presented quotes were chosen as they demonstratively represented the relationship between healthcare personnel and endometriosis patients while still summarising the prevailing views among the participants.

4.4 Reflexivity and Source Criticism

When choosing qualitative interviews as a method, you need to consider that the research interview is not a conversation between equal parties since it is me, the researcher, who defines and controls the situation (Kvale & Torhell, 1997). Ramazanoglu and Holland (2002) express the problems experienced in interviewing as researchers can represent the lives and ideas of the researched as similar or different across any divisions between them. Making knowledge claims across differences means taking responsibility for interpreting the social existence of others, and so is normative, personal, political, and epistemological. As a researcher, I am in a powerful position to specify what differences exist, what they mean, whether they matter, and how they should be represented in research findings. This power lies in authority, or the ability to name differences and specify relationships' boundaries and meanings. The researcher exercises power by turning people's lives into authoritative texts by hearing some things and ignoring or excluding others (Ramazanoglu & Holland, 2002).

A common criticism is that qualitative research interview studies lack objectivity, mainly depending on the human interaction essential to the interview situation (Kvale & Torhell,

1997). Ramazanoglu and Holland (2002) convey that researchers cannot set aside their language, life, and understanding when they produce their interpretations. It is not possible to be entirely objective and free of values, as the research subject is usually a subjective choice and something that arouses interest. As a person personally affected by the diagnosis of endometriosis, I have to acknowledge the position I have and work hard to have an objective approach to the theoretical starting points and the empirical material of the study. If I had not had my own experiences seeking medical treatment for symptoms of endometriosis, I would not have started questioning the extent of power that healthcare has over an endometriosis patient. Every step of the way, I had to reflect on my values to avoid unintentionally influencing the direction of the conversation in the interviews and the analysis of the material. I acknowledge that my role as a qualitative researcher and with an endometriosis diagnosis linked to questionable experiences are a part of my research process and that my assumptions and beliefs will influence the research process. Thus, it is already known that reliable endometriosis care is absent. Therefore, someone without my experiences could also enter with the same view as me but need a more extensive understanding of what it could mean for someone who has to go through it.

An interview about healthcare experiences can be a sensitive subject and thus make the respondent uncomfortable; also, the context in which the interviews take place and how the researcher chooses to ask the questions can affect whether the respondent feels uneasy. Based on my own experiences, it can feel easier to share complex and traumatic moments with someone who not only listens but also confirms and validates the trauma you have been exposed to. Therefore, I argue that my own experience can work as an advantage in the interviews as the participants have a conversation with someone whom they can relate to and someone who understands their situation without having to explain every step of the way, which you may have to do for someone else who is not familiar with the process. Since the interview guide was semi-structured, this enabled conversations that were necessarily not only created by the interview questions but also by the respondent. For some participants, it works better, while others prefer more structure and just answer the prepared questions.

By doing 20 qualitative interviews, I do not intend to be able to testify for all endometriosis patients in Sweden; the results can instead be seen as a complement from a larger perspective where the results show different interpretations and attitudes that exist. Qualitative implies emphasising the qualities of entities, processes, and meanings that are not experimentally

examined or measured in quantity, amount, intensity, or frequency (Denzin & Lincoln, 2011). Kvale and Thorell (1997) describe the goal of a qualitative interview study as achieving general knowledge within specific areas to comment on how it might be to generalise from within the qualitative method. Denzin and Lincoln (2011) mean that qualitative researchers seek answers to questions that stress how social experience is created and given meaning.

5. Results - A Physically Draining Struggle

“It’s exhausting; it makes you feel so terrible; it’s like I’m feeling worse right now from the reception I get from health care than the endometriosis itself; it shouldn’t be like that.”

“Katja”, 34 years old

This frustration that “Katja” describes is a common conception among the participants in this study, but also in Grundström et al. (2018; 2020). It is built up over years of trying to be heard and to get adequate help or treatment from Swedish healthcare. The physically draining process was many times described with the phrase: *“You have to be healthy to cope with being sick.”* To exemplify this quote, we can go back to “Katja’s” experiences; she struggled with adhesions in her intestines due to her endometriosis, which meant she had chronic pain and menstruated from her rectum. Nevertheless, she was questioned by healthcare personnel if she was asking for sick leave only because she was lazy. This is more or less the norm as an endometriosis patient, where one must defend oneself against prejudiced healthcare personnel who all too often ask if the pain is just something you made up. “Katja” and the other participants describe these recurring interactions with healthcare personnel as a struggle where history repeats itself.

These experiences are what I will evaluate and analyse further in this chapter, in eight parts:

- 5.1 The Reception of Endometriosis Patients
- 5.2 How Appearance and Behavior Affect Reception
- 5.3 Being a Teenager with Endometriosis Symptoms
- 5.4 Lack of Knowledge
- 5.5 Placing the Responsibility on the Patient
- 5.6 Not Being Included in Your Treatment
- 5.7 Becoming Your Own Specialist
- 5.8 The Lottery of Receiving Good Care

5.1 The Reception of Endometriosis Patients

“The reception you get from healthcare is “You just have to learn to deal with the pain”. So you start to question yourself, like, have I imagined it? Am I not in so much pain? You kind of start to doubt yourself as a person. Is it me who is sensitive, or why can't I cope when everyone else copes with their period pain?”

“Paulina”, 30 years old

These narratives, here demonstrated by “Paulinas” quote, are similar to the ones in Grundström et al. (2018; 2020) and Young et al. (2020), where the participants describe healthcare personnel's reception of them unsympathetically by questioning and contradicting the patient's experiences and by normalising their symptoms of pain, both severe menstruation pain and deep pain in connection to penetrative intercourse. The repetition of these receptions by healthcare personnel made the participants feel like a burden and, as “Paulina” describes it, made them doubt if they were just sensitive and if everybody else also experienced this sort of pain. For “Paulina” to start to question her own pain indicates that the healthcare’s opinion weighs stronger than her own experience. She and the other participants describe their contact with Swedish healthcare as a journey where they initially had much trust in them because it is what they were raised to have. The healthcare system's opinion is valued as the truth as they are an authoritarian power in society. This trust is what Foucault describes as *connaissance* knowledge that is didactic and received knowledge (Jackson & Mazzei, 2012). This trust made the participant question themselves at the start and not the healthcare personnel because they expected and assumed they possessed the knowledge. When the pain then gets worse, they tell themselves that they just have to bite the bullet and that this is how it should be to be a menstruating woman until they reach a point where it is no longer possible to persuade themselves that what they are experiencing is normal. This *connaissance* knowledge of trusting healthcare personnel starts to be questioned when they gain more experiences that prove the opposite. With time, their perception of healthcare develops into *savoir* knowledge constructed in experience with their reception in the Swedish healthcare system (Jackson & Mazzei, 2012). The experienced struggle did not end when one received a diagnosis; it was merely experienced to validate one's symptoms. Some participants said that they felt like they had reclaimed some power from healthcare by receiving their diagnosis but that it rarely changed the healthcare personnel's reception of them as patients.

Narratives from participants in this study of being viewed as “*junkies*” while also not receiving effective pain relief and almost no pain medication with opioids coincide with what Grundström et al. (2018; 2020), Young et al. (2020) and Samulowitz et al. (2018) demonstrates. The 39-year-old participant “Petra” told me that she was referred back and forth between different physicians concerning her pain-relieving treatment, which made her experience frustration and shame for asking about these pain medications. The feeling of shame is an effect of healthcare's exercise of power as it disciplines the patient to act according to the pastoral perspective of power (Young, 2003). Therefore would “Petra” not experience this feeling of shame if it was not in relation to healthcare's perception of women with endometriosis according to them, in this case, a “junkie”.

Being referred around like “*a hot potato*” is not something that was only linked to medical pain treatment, as participants talked about being referred around to many different personnel: midwives, general practitioners, and gynaecologists. The 36-year-old participant “Ebba” described it as: “*It feels like you have revolving doors on your vagina.*” “Ebba” used humour to signify the absurdity and the frustration she had of needing to meet several different personnel through the exposing experience of a gynaecological examination. By meeting so many gynaecologists “Ebba” also told me that all of them said different things to her about her endometriosis cysts. One told her: “*You need to check this cyst every six months*”. The next one said: “*But “Ebba”, you're smart; you understand well that you don't need to check these constantly; it doesn't change that quickly*”. The third one bluntly asked her if she was sure she even had endometriosis. While the fourth one asked: “*Oh, do you know you have a cyst here? Has anyone checked it for tumour markers?*”. This made “Ebba” doubt what knowledge the gynaecologists had about her diagnosis. She said: “*I don't know who I should trust.*” Then, she continued with: “*Nor is it my job to tell them what their colleagues are saying.*” “Ebba” once again uses her humour to show her frustration at the absurdity of her experiences. “Ebbas” constructed knowledge is produced in experience and in relation to the gynaecologists and what Foucault refers to as *savoir* knowledge, which defines and changes how “Ebba” participates in the context of her endometriosis examinations (Jackson & Mazzei, 2012). More participants talked about physicians doubting and questioning other doctors' diagnoses, which was experienced as another level of scrutinising their symptoms. The participants expressed, as mentioned, that they felt validation receiving their diagnosis and a sort of “*I told you so*” sensation. Then, when

another physician questioned the diagnosis, they experienced a second wave of trivialisation of their symptoms. This made some participants question whether their diagnoses were fully established or could be removed. This created a prolonged power imbalance, where the physician was perceived to have the upper hand.

5.2 How Appearance and Behaviour Affect Reception

“I wouldn't go there in sweatpants or maybe wear a lot of make-up, for example. I still think that doctors usually judge how healthy and clean you look.

“Lisette”, 28 years old

From an intersectional perspective of how the participants experienced the reception, some expressed that healthcare personnel's reception of them could differ depending on appearance. “Lisette's” quote is linked to the discourse of *“looking too healthy”*, where endometriosis patients who seek emergency care have experienced that when they look *“to put together”*, they are more often distrusted about how much pain they are experiencing. The 52-year-old participant “Marianne” gave an example of when she experienced this: *“A nurse at the emergency gynaecology clinic stopped me and said that I couldn't possibly be in that much pain because I was so tanned. So apparently, you can't be tanned and look healthy while having pain.”* These narratives coincide with Samulowitz et al. (2018) that women are mistrusted when they “look too good”, as in *“you can't be sick”*. According to these comments, what is often considered conventionally attractive does not equate to being treated better as an endometriosis patient but rather the opposite. When patients choose strategies not to experience distrust (for example, not wearing much make-up), they discipline themselves to the pastoral power while trying to enable their chances of receiving care (Waring & Latif, 2018). These events will allow the relation to continue, as nothing to my knowledge is done within the healthcare system to oppose or challenge these prejudiced views.

Participants also experienced that confrontational behaviour against healthcare personnel could affect the reception they received. The 26-year-old participant “Liv” described how she adjusted to this: *“I try to make it easier for them to have a positive attitude towards me so that they don't have to end up in a defensive situation.”* This statement also indicates an individual disciplining themselves to enable their chances of receiving care from healthcare, and she comes to these conclusions from earlier experiences (Waring & Latif, 2018). This

“*defensive situation*” is described similarly to how the physicians in the second category of Nimmon and Stenfors-Hayes's (2016) study described doctor-patient encounters as a struggle. “Liv” is thereby disciplining herself so that the physician does not experience their medical appointment as a “struggle” (Waring & Latif, 2018).

The 28-year-old participant “Lisette” described being non-confrontational from a developed perspective, why it was a selected strategy and how it was shaped by a societal norm of how women should act: *“You don't want to be perceived as annoying, as a hysterical woman, and I think we are afraid of that in general. Therefore, it will be a lot of “Thank you so much for taking your time on med and for letting me come here”.* “Lisette” describes here how the hysterical diagnosis has influenced the perception of how an endometriosis patient is perceived to behave. Any aberrant behaviour that fails to adhere to the social expectations of women is still linked to being hysterical (Johannisson, 2005; Jones, 2015). “Lisette” describes how these social expectations influence her to express gratitude. If she acted confrontationally instead, which is perceived as more of a masculine attribute, the physicians could view her as hysterical (Samulowitz et al., 2018; Johannisson, 2005; Jones, 2015). This indicates an obsolete mentality linked to the concept of a woman's pain in healthcare (Folkmarson Käll, 2012), which was something the 34-year-old participant “Katja” compared to the metaphor of: *“It was Eve who ate the apple. Therefore, we should suffer in pain. It feels like that's the mentality that it's the woman's lot in life; the woman must be in pain because the woman ate the apple.”* “Katja” used humour to paint the picture of her frustration with the absurd, outdated mentality in healthcare by using the biblical metaphor that all women must suffer pain (during childbirth) because Eve was greedy and took a bite of the forbidden apple in the Garden of Eden: *“I will greatly multiply your pain in childbearing; in pain you shall bring forth children, yet your desire shall be for your husband, and he shall rule over you.”*

(Genesis 3:16, 20; 4:1–2)

5.3 Being a Teenager with Endometriosis Symptoms

“When I was younger, a doctor bluntly said, “It’s just your imagination; maybe you just need a little attention. Is that what you want?”

"Paulina", 30 years old

The most recurring intersectional aspect of receiving bad reception from healthcare personnel in this study was age or lack thereof. The participants who had to start seeking medical care in their early teens shared similar narratives to the bloggers in Grundström et al. (2020) on the struggles of being completely reduced into being *“too young to experience these symptoms”* and, in many cases, described as *“attention-seeking”* or viewed as a *“silly teenager who does not understand that it hurts to menstruate”*. These statements indicate a lack of knowledge within healthcare, where there is little to no understanding that symptoms of endometriosis could develop during puberty.

I interpret the reception of minors as healthcare generally having a narrow frame of reference on the concept of children, in which children are viewed as “not-yets” dependent on adults (Moosa-Mitha, 2005). This concept would mean that when a teenage girl expresses pain, the physician does not consider her opinion reliable. A clear example of this, where it becomes apparent that some healthcare personnel do not view minors as capable “not-yet-agents”, is described by the 17-year-old participant “Fia.” She said that healthcare personnel talked *“over her head”* to her parents rather than directly to her, even while discussing very personal questions. “Fia” experienced these situations as degrading to her as a capable individual.

“Fia” also told me about another experience: *“I’ve been told once by a doctor that I’m taking time away from them, that it’s a waste of doctors and resources to spend on me because I’m just a child.”* This account also indicates a narrow frame of reference on the concept of children, that she, as a child, is a waste of time and resources that should instead be used on more “important (adult) patients.” Choosing to say something like this directly to the minor and not to their accompanying parent is a statement of its own. The physician is placing the responsibility of wasting time and resources on her; the physician is disciplining “Fia” through the concept of pastoral power (Waring & Latif, 2018). It also indicates that the physician thinks this statement has no consequences. This notion is shared by 33-year-old

“Karolina” who experienced these receptions as an active choice made by the personnel. She said: *“It’s easier to silence a 17-year-old than someone who is 30; I think they take advantage of that.”*

When “Fia” felt frustrated that her symptoms were reduced because of her age, she told me: *“I’ve tried a few times to look older to get more respect before they might ask about my age.”* The 20-year-old participant “Lea” had similar experiences: *“I had to act older and tough to stand up for myself and not to take any crap from the doctors.”* The perception of age in this context is that adults are the norm and are viewed as more capable agents in healthcare. These two participants, therefore, discipline themselves into these frames of reference in the hope of receiving a better reception (Waring & Latif, 2018).

5.4 Lack of Knowledge

When conducting the interviews, it became apparent that healthcare personnel rarely suspect endometriosis as a diagnosis, which was also a conclusion Young et al. (2020) reached in the Australian healthcare system. This exposes the lack of knowledge within the Swedish healthcare system when the physicians cannot bring all symptoms together and explicitly lift the suspicion of a diagnosis. Some participants described how someone close to them had lifted the question *“Maybe you have endometriosis?”* or through Google searches on their own and linked their symptoms to endometriosis, and after that, questioned healthcare about the possibilities of a diagnosis. This initial interaction was described in this study and by Young et al. (2020) as a struggle, as the physician often became defensive when the patients came to the meeting with a suggested diagnosis. Society values medical science as *the truth*, and doctors are put on a pedestal, as they are the ones who “possess” this truth (Foucault, 1971). When a patient comes up with a suggestion for their own diagnosis, it unbalances the doctor's pedestal as it is now the patient who brings *the truth*. Which makes some physicians act defensive or try to work against *this truth* by instead trying to find things that contradict the suggested diagnosis. This reaction goes in hand with Nimmon and Stenfors-Hayes's (2016) second category of physicians, who described doctor-patient encounters as a power struggle and perceived their power as waning in the context of doctor-patient interactions. Therefore, as both parties experience these interactions as frustrating, it corresponds with what Samulowitz et al. (2018) described: encounters between a woman with chronic pain and her physician are experienced as a struggle by both the patient and the physician.

Other participants described their diagnoses as being established by chance while doing other procedures. Some of them had normalised their period pain for years and had no idea what endometriosis was before they received their diagnosis. Still, for most of them, it came as a moment of realisation and validation for all the years of suffering from pain and other symptoms. Some expressed frustration, not just at healthcare's lack of knowledge, but also at society's normalisation of period pain.

In some medical appointments, the participants had experienced physicians who explained that they lacked knowledge and could not help the patient further; these experiences were described as positive, honest and straightforward. The problem, however, was that these interactions were rare, as it was more common with experiences that 26-year-old “Ronja” described as: *“being thrown between people who are just trying to get rid of me”*. Even more often, the participants testified about healthcare personnel closing the participants' medical cases rather than referring them to another physician. This made the participants experience that the healthcare personnel did not care to help them and that they were viewed as *“lost cases”* that only took up time from other, more important patients. This created a lack of trust and made some of the participants unwilling to seek medical care in order not to have to expose themselves to something that could be traumatic, as the sheer thought of contact with healthcare felt physically draining.

When a doctor would rather close a patient's medical case than refer them to someone else, it could signify that the doctor does not want to be viewed as unknowledgeable as they are assumed to “possess” *the truth*. If they instead prompt that these symptoms are normal or there is nothing more to be done, they are still the ones to “possess” *the truth* instead of admitting their shortcomings (Foucault, 1971). This behaviour does not apply to all doctors, as some were described as truthful about their lack of knowledge and, therefore, helped the patient onward with a referral to another doctor.

5.5 Placing the Responsibility on the Patient

Foucault's concept of pastoral power describes how doctors are society's modern pastors by disciplining patients through clinical categorisation, surveillance, and contemporary health policies to encourage the patients to make more appropriate lifestyle choices and care for

themselves (Waring & Latif, 2018). Narratives throughout this study show the exercise of pastoral power by physicians placing the responsibility for the symptoms of endometriosis on the patients and that their lifestyle choices must change. Two of the participants had experienced their symptoms being reduced to depend on their weight; 33-year-old “Karolina” had been told she was too skinny the first time she sought care for her symptoms. The doctor had bluntly told her to gain weight and that the symptoms would then disappear. The 32-year-old participant “Josefina”, had experienced her symptoms over and over again, being blamed on her being overweight: *When I was diagnosed with endometriosis, I weighed between 50-53 kg. Then, I was given medication for depression, which made me gain 60 kg in a year. So from then on, it's always: "You weigh too much". Even though I was thin once and had the same symptoms.*” These encounters allude to Folkmarson Käll's (2012) intersectional perspective that pain is a gendered experience and weight is one of the categories that could influence how one's pain is seen and treated. To blame one's body shape as the reason for endometriosis pain is to simplify and reduce what the patient is going through and could be used as a shortcut for physicians to close “difficult” medical cases.

The aspect of pregnancy is often a charged subject when it comes to the discourse about endometriosis. To this day, participants were still told by healthcare personnel that pregnancy would help them with their symptoms or even promised that it would cure their endometriosis. Like the narratives in Grundström et al. (2018; 2020), the participants said this advice felt intrusive as they were unhappy that healthcare personnel tried to influence such a big life decision. However, it was also described as provoking that these myths still exist in the Swedish medical system. The 43-year-old participant “Eva” was told by a physician only last year: *"It's a shame that you are too old that you can't get pregnant because pregnancy cures endometriosis"*. With this comment, the doctor blames “Eva” for not “treating” her symptoms earlier by getting a child for her health benefit. This stubborn and incorrect old myth was something almost every participant mentioned and, of course, was disproved by those participants who had children. Jones (2015) describes these obsolete myths of pregnancy linked to the notion of anchoring the wandering womb in hysterical women. Hysterisation was used to discipline women to fit into their functions in the reproductive sphere. As a disciplinary measure, the hysterisation pathologised women who deviated from normative femininity (Johannisson, 2005). This notion bleeds through to today's endometriosis patients with these recommendations. The participants, however, experienced the comments about pregnancy as treatment or a cure solely to showcase the healthcare

personnel's ignorance and lack of knowledge about endometriosis and as a sign for them not to seek any care from them onwards, which proves them being agents who navigate their lives by their own decisions (Foucault, 1991).

One participant had experienced the discourse of pregnancy beyond the notion of pregnancy as a treatment; 17-year-old “Fia” was once told by a physician: *“That I shouldn't have children in the future, and so I said “Can't I have it?” and then they said, “You can, but you shouldn't do that because then you might spread the disease”.* This doctor places a responsibility on “Fia” that indicates that if she would get children, she would be selfish because she would expose them to the risks of having endometriosis. The comment also indicates the assumption that life is not worth living if you have endometriosis, according to this physician. Even though the comment “Fia” received is inconsistent with the myth about pregnancy as a treatment, I do think both arguments show how doctors rather nonchalantly take the liberty to make life-changing suggestions: *“You decide for yourself, but there is a right and a wrong choice”* even though when they are evidently not grounded in evidence-based medicine.

5.6 Not Being Included in Your Treatment

There's no room for discussion on what I think. Everything I say might not be correct, but I would like to have a saying and not just be met with, “No, I have said this, and this is what we are doing now, period.”

“Petra”, 39 years old.

Similar to the narratives in the Australian study by Young et al. (2020), the participants in this study feel that healthcare personnel did not fully include them in deciding and discussing their treatment. They expressed that it often felt that their opinions about their bodies were viewed as not as necessary in the decision-making as the healthcare personnel's perception of the situation. The 26-year-old participant “Ronja” felt pressured by healthcare personnel to continue with hormone treatments that gave her psychological side effects, which she experienced as an exercise of power: *“I wouldn't still be on these medications if they didn't have that power to say that I had to do so.”* She continued, *“You should always stick to what you feel is best for yourself, but it is difficult to do so during these appointments.”* The reason why the participants often felt subjugated during appointments was due to the dependence

they experienced they had on physicians as they were described as gatekeepers of them receiving help with their endometriosis. The physicians were, in many cases, defined as yielding this power; 32-year-old “Josefina” gave an example of when physicians promptly said her pain was located in the area of her appendix, where it was not, but they would not listen to her. In the discussion about why her opinion was invalidated, she said: *“It’s the doctors that think they know someone else’s body better than you know yourself.”*

The lack of empathy by healthcare personnel was also expressed to be an indication of the exercise of power as 28-year-old participant “Lisette” said, *“No one has ever asked me how it feels, or how I feel, or how did this information land, or what do you think. They talk to me and not so much with me.”* By viewing these experiences from Butler’s (2002) perspective on agency, these repeated interactions become the norm, and agency forms by the participants concluding that their thoughts and feelings about their bodies are viewed as less relevant than healthcare personnel’s supposed knowledge. The healthcare personnel were also described as nonchalant, not caring about their patients or jobs. The 52-year-old participant, Marianne, spoke about endometriosis genuinely being viewed as unattractive to work with within gynaecology. The 24-year-old participant and medical student, “Laura”, also mentioned this: *“It has noticeable low status, gynaecology in general, but mainly endometriosis. No one thinks it’s cool to work with it, and that is sickeningly provocative, and it makes me upset.”* The 52-year-old participant, Juliette, effectively summarised all of these experiences and mechanisms that affect the situation: *“You are always inferior as a patient, but when you have something a bit diffuse, underresearched, and difficult to diagnose, that is also a woman’s disease with a dash of 19th-century hysteria mixed in, it will never be easy.”*

5.7 Becoming Your Own Specialist

“It took a few years of this before I felt that I’d listened to them long enough to dare say what I wanted to get out of this.”

“Ronja”, 26 years old

There was a general experience among the participants that with age comes experience and gained knowledge, which leads to confidence to speak up against yourself. As Mahmood (2005) suggests, agency develops as a capacity for action that specific relations of subordination enable and create. This progress is captured in the 26-year-old “Liv” quote

about her gained trust in herself: *“I have more knowledge, and I also have more trust in my own experiences and my own symptoms.”* Being subjected to trivialisation for years, when the symptoms keep on getting worse, there comes a boiling point where enough is enough. The symptoms are valid and should be treated, but to get that treatment that is deserved, endometriosis patients start to develop strategies that they think can enable their chances. Almost every participant said that they had, at some time or every time, prepared themselves before a medical appointment by writing down questions or arguments they could use to boost their chances and to get some answers. This created a sensation of calmness because even if they did not need to use these notes, they felt backed up by them, just knowing they had them.

The 28-year-old participant “Lisette” told me why she felt that she needed to be prepared for an appointment: *“Every single time I've been there, they want to talk to me about contraceptives. Therefore, I have a prepared defence speech about why I don't want it.”* Narratives like “Lisettes” indicate that the participants are agents who decide, choose, and navigate their medical appointments to complement their lives (Foucault, 1991). However, these defence tactics were not always appreciated by the healthcare personnel, as described by 26-year-old “Ronja”: *“Sometimes I have expressed that I don't want to go on the pill, and then they become defensive”* This shared experience is connected to the fact that healthcare does not want to offer anything else than standard hormone treatment, and if you are not willing to go through with one or more pills or IUDs combined you shall go untreated. The concept of having a low quality of life because of psychological side effects or still feeling pain even if you are not bleeding anymore is overlooked and only met with a proposal of another pill to try or add. This means that many of the participants would instead go without any prescribed medical treatment, even though it meant that their endometriosis could worsen.

Participants felt similar to the Australian women in Young et al. (2020), that they needed to practice self-care for their endometriosis symptoms. The 36-year-old “Ebba” said: *“I think that for me it has always been the case that you go to healthcare and they say “No, this is not something we can do anything about” then I realise that okay, I have to find strategies myself.* She continued: *“I have control and feel good in everyday life, and I have found strategies not to have pain when I menstruate and to eat so that I don't have further problems. I have solved all of that myself.”* Similar to “Ebba”, all the other participants gained knowledge by reading

online about their diagnosis. Many expressed that this was the only way for them to receive this information as healthcare personnel were described as lacking general knowledge or did not seem to care to inform their patients about the diagnosis. We can view “Ebbas” quote from Butler's (2002) perspective of agency, where they suggest that it occurs in and through the moment of an act. When “Ebba” goes to medical appointments and experiences rejection on repetition, it is through this action that the subject comes into being, and this repetition of rejection becomes a norm. “Ebba” exercises power by identifying this repetition of rejection and chooses to solve that on her own. This way, the effect of healthcare’s rejection forms agency within “Ebba”, which enables her to find quality in life while having endometriosis.

If self-care and lifestyle changes were not enough, going abroad to pay for treatment was another option. However, this was very expensive and something not everyone could afford. The 24-year-old “Laura” said that she might seek treatment abroad and described it as an *“act of desperation”* when the Swedish healthcare system was reluctant to help with treatment. “Liv”, a 26-year-old participant, was denied a laparoscopy in Sweden: *“I had surgery abroad and in total, I probably put 100,000 KR on it, and that's much money, but it meant that I went from being on long-term sick leave to being able to work for five years without being on long-term sick leave.”* “Livs” results from her laparoscopy abroad clearly showed how she made an adequate medical decision to increase her well-being, based on her being the specialist on her own body and endometriosis symptoms.

5.8 The Lottery of Receiving Good Reception

“It is a coincidence that you will come in contact with the right person, and whether you do or not is a lottery.”

“Eva”, 43 years old.

Not all interactions between endometriosis patients and Swedish healthcare are consistently negative experiences. During the interviews, the participants shared positive experiences, which also conforms to the narratives in Grundström et al. (2018; 2020), where healthcare personnel acknowledge the patients' frustration and pain and make them feel valid, visible, and sane. Being seen as an individual, not a body or object, was also critical to a positive healthcare experience. The 30-year-old “Paulina” described it as *“being spoken to as an equal”*. The 52-year-old “Juliette” gave an example of when she finally met a physician who

did this: *“She validated me as a patient, my feelings, my experiences and my impressions.”* “Juliette” then did what many other participants described as *“cling on for dear life”* and did everything possible to continue to see this physician who had broken the repetition of rejection and trivialisation. Meeting a physician like this was also an awakening to realise how bad some earlier experiences had been, as they now had another reference frame. It became an essential analytical tool for the participant navigating old and new interactions with healthcare personnel.

However, a recurring metaphor used by the participants to describe the possibility of meeting a physician who validated one's symptoms is used by “Eva” in the first quote, where such a meeting was compared to participating in a lottery. Some participants expressed that they still have not had a lottery win yet, which demonstrates the width of the lack of knowledge about endometriosis as some of these participants had been in regular contact with healthcare about their symptoms for 10-20 years. This general lack of reliable medical appointments created anger, frustration and, in some cases, despair. All participants expressed that they wanted to spread awareness about endometriosis to make a societal impact. This occurrence corresponds with Mahmood's (2005) perspective that agency develops as a capacity for action that these relations of subordination enable and create. Participating in this study and telling others about their experiences was described as an active choice in this direction. Some participants were active on social media or in organisations or had been interviewed by journalists about their experiences. One of the participants told me: *“I think it's nice when I am able to get angry because it means I have some energy. You need the energy to be angry. Otherwise, you're numb and sad, but if you're angry, you have at least some energy to direct the anger where it belongs.”* This quote goes back to *“You have to be healthy to cope with being sick.”* As to describing how physically draining it is to have any contact with healthcare as an endometriosis patient while dealing with chronic pain. Therefore, there could be very little energy left to direct into trying to change an obsolete and misogynistic healthcare system. I will always be highly grateful to the participants who used their energy, frustration and anger to participate in this study; you are all such impressive agents and have been put through experiences no one should have to endure.

6. Discussion

This thesis expands on an established but overlooked area of the medical field by placing it within the context of Gender Studies by analysing the discriminatory power relation between endometriosis patients and the Swedish healthcare system. Hopefully, this study could inspire others to conduct similar studies, as the number of individuals who wanted to participate indicates that so many narratives about these experiences need and should come to light. If more studies repeatedly show the lack of reliable endometriosis care, it might finally be taken seriously to trigger a change. Hallströms's (2024) contribution to gender studies with her article about *endo time* was published at the end of March this year (briefly summarised at the end of 2.3). I found out about her article too late to use it for my thesis. Therefore, I highly encourage others to use her article as an analytical tool or theoretical framework in future studies about endometriosis experiences.

While conducting the interviews, it became clear that Swedish healthcare personnel lacked knowledge in combining symptoms to form a suspicion of endometriosis diagnosis, comparable to the Australian findings in Young et al. (2020). Also, similar to Australian healthcare, if the patients themselves tried to mention their own suspicion of an endometriosis diagnosis, it often created resistance from the physicians. As stated earlier, this reaction reflects doctors who can not handle patients with more knowledge than themselves; they have to conclude on their own, or it is irrelevant and simply not true, as they have the power and knowledge. When this is put out of play, they choose only to see everything that opposes what the patient is saying so that they can keep on having the upper hand as they are viewing the patient-doctor encounter as a power struggle, as the second category of doctors in Nimmon and Stenfors-Hayes (2016). A study similar to Nimmon and Stenfors-Hayes (2016) on doctor-endometriosis patients' encounters with gynaecologists (and midwives) could be beneficial in evaluating how the healthcare system could improve the reception of endometriosis patients. The similarities between Sweden's and Australian healthcare's inability to combine symptoms to form suspected diagnoses and their reception of patients doing it themselves clarify the global lack of knowledge of the diagnosis of endometriosis.

I noticed early on while conducting the interviews that we often returned to the concept of the first time seeking care for endometriosis symptoms as a minor and how it usually was the

starting point for the participant's normalisation of their period pain. If a doctor told them there was nothing wrong with experiencing this sort of pain, they tried telling themselves that too; therefore, some went on for years with severe period pain to finally receive their diagnosis as adults. Some expressed it as feeling cheated by the healthcare, robbed of a life they never got, because if they could have gotten their diagnosis as teenagers, they could have started treatments that possibly could have prevented several years of pain. The question “*What if?*” is relevant when discussing Swedish healthcare's inability to help teenagers with endometriosis symptoms professionally, as their lack of knowledge can cause suffering that could have been prevented.

The 17-year-old participant “Fia” observed that the healthcare adult norm made her feel she needed to try to look and act older to be treated as a person. The older participants confirmed this norm by saying that they found it easier to navigate and be heard by healthcare personnel when they became older and more experienced. I do think there is so much more to uncover here about minors in endometriosis healthcare. Therefore, if I ever get the chance, I would like to do my postgraduate degree on minors with endometriosis symptoms and how they get treated within the Swedish healthcare system, as they are, from an intersectional perspective, subjected to discrimination and marginalisation on the grounds of being minors, assigned females at birth and as endometriosis patients (Crenshaw, 1991). They are an even more unresearched group than endometriosis patients overall.

During my search for participants, I only specified that the participants did not need an established diagnosis, live in a particular place or have a certain age to partake. I did that to collect a diverse age range and population from all around Sweden. However, the participants were predominantly white, heterosexual, cisgender women. Therefore, it would be interesting to conduct the same process but with a more diverse group, from an intersectional perspective, to see if there is any difference when there are more grounds that could make them vulnerable to discrimination than what has already been discussed in the results. For example, are there studies concerning midwives and doctors in maternity care that show structural racism (Robertson, 2015). I doubt this would also not be the case for racialised individuals in endometriosis care, as it usually includes the same occupational group as in maternity care.

I hope I have done justice to the participants' personal experiences throughout this thesis and process. As the researcher, I have been a gatekeeper of their narratives; I have been in a position of power. Therefore, I needed to work with the same perspective as the physicians in the first category of Nimmon and Stenfors-Hayes (2016); it is an ethical responsibility to be mindful of the effects of power in the relationship and not take advantage of the position of power. There is an argument to be made that I, as the researcher of this thesis, could be seen as contradictory; whilst I share experiences with the participants, I am also in a position of power similar to that of the healthcare personnel I am critical of. My view of this is that once in my life, my endometriosis diagnosis could finally be put to use as my own “thinking tool” or “gadget” to both help me navigate interviews about traumatic experiences and help me be responsible about my position of power.

7. Conclusion

7.1 The Participant's Experience of the Swedish Healthcare Personnel's Reception of Them as Endometriosis Patients

Through repetition of rejection and trivialisation of their symptoms, the participants experience the healthcare's reception of them as a physically draining struggle. The repetition of these receptions by healthcare personnel made the participants feel like a burden and doubt if they were just sensitive. Being viewed as “*junkies*” while also not receiving effective pain relief and almost no pain medication with opioids and being referred back and forth to different personnel: midwives, general practitioners, and gynaecologists were shared experiences.

Through the intersectional perspective on healthcare reception of endometriosis patients, it was experienced that minors were treated worse as they often were told that they exaggerated their pain, did it for attention or were too young to experience these symptoms. The participants' narratives of how the healthcare personnel interacted with them during medical appointments indicate that they do not perceive minors as individuals who are capable of speaking for themselves and have any understanding of their bodies.

The participant's appearance and body shapes were also something the participants expressed that affected the reception they got. Behaving outside the feminine societal frame of reference by being confrontational was likely to trigger a power struggle that was not appreciated from the healthcare's perspective as it made them regard one as an annoying patient. This perception of endometriosis patients could be interpreted as a connection to how the diagnosis of hysteria still affects the perception of how a woman “should or should not behave” while seeking care.

The Swedish healthcare system lacks knowledge in combining symptoms with raising suspicion of an endometriosis diagnosis. Patients are responsible for reaching this conclusion. However, healthcare personnel rarely appreciate this conclusion, as it is interpreted as a power struggle in which they must defend themselves and their knowledge.

From a pastoral perspective on power, physicians impose responsibility on patients for their symptoms, and by repeating these interactions, they discipline endometriosis patients to behave in the way they prefer. This discipline is indicated in how the participants strategically change their appearances and interact with personnel to avoid being perceived as confrontational. An aspect where the expression of pastoral power becomes prominent and challenged is when it comes to the discourse where healthcare personnel insinuate pregnancy as a curative treatment for endometriosis. This advice felt intrusive, as healthcare personnel tried to influence such a big life decision, as well as provocatively, that these myths still exist in the Swedish medical system. The participants interpreted the advice about pregnancy as a curative treatment as a sign of a lack of knowledge and that the physician was not capable of helping them further on.

The narratives in this interview study share similarities to the ones in Grundström et al. (2018; 2020) and Young et al. (2020). The similarities indicate that healthcare's reception of endometriosis patients is a shared experience that does not only relate to Sweden's healthcare reception.

7.2 The Participant's Power over Their Endometriosis Treatment

Narratives about experiencing healthcare personnel as nonchalant and as if they did not care about their patients or their jobs were common. The participants experienced that they were not included in deciding and discussing their treatment with healthcare personnel. They often felt that their opinions about their bodies were considered less in the decision-making process than the healthcare personnel's perception of the situation. Some felt pressured by healthcare personnel to continue with hormone treatments that gave them psychological side effects, which often got dismissed by the healthcare personnel. This diminishing behaviour created frustration among the participants as they experienced dependence on healthcare as gatekeepers of receiving help with their endometriosis.

The participants felt they needed to practice self-care for their endometriosis symptoms and acted upon this as agents; they learned about self-care and their diagnosis by reading online. Many expressed that this was the only way to receive this information, as healthcare personnel were described as lacking general knowledge or not seeming to care to inform their patients. When the participants get denied the treatment they deserve and need, they develop tactics they think can enable their chances for their next medical appointment. Almost every participant said that they had, at some time or every time, prepared themselves before a medical appointment by writing down questions or arguments they could use to boost their chances. This created a sensation of calmness because even if they did not need to use these notes, they felt backed up by them, just knowing they had them.

The general conception among the participants was that with age came experience and gained knowledge, which indicates a cultivation of agency that influences confidence in speaking up against yourself. Meeting a physician who breaks the repetition of rejection and trivialisation was experienced by some as an awakening to realise how bad some earlier experiences had been, as they had gained another reference. It became an essential analytical tool for the participants to navigate old and new healthcare personnel interactions.

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Attachment 1. Interview Request



Förfrågan om att delta i en intervjustudie om maktrelationen mellan den svenska hälso- och sjukvården och endometriospatienter

Syftet med studien är att ur ett patientperspektiv undersöka maktrelation mellan den svenska hälso- och sjukvården och endometriospatienter. Studien är ett examensarbete på avancerad nivå inom genusvetenskap och är en del av utbildningen Gendering Practices vid Göteborgs Universitet, men deltagare från hela Sverige välkomnas genom digitala intervjualternativ. Studien vänder sig till dig som har en endometriosdiagnos, saknar diagnos men är under utredning eller att det finns misstanke om endometrios.

Intervjuerna genomförs under februari-april 2024 och kommer att beröra dina upplevelser av hälso- och sjukvårdspersonals bemötande, samt kring den vård som du har erbjudits. Intervjun beräknas ta mellan 30-60 minuter och genomförs på plats i en ostörd miljö eller via Zoom eller Teams om du befinner dig på annan ort eller föredrar att mötas digitalt. Intervjun kommer att spelas in och skrivas ut i text.

Den information som du lämnar kommer att behandlas säkert och ingen obehörig kommer att kunna ta del av den. Redovisningen av resultatet kommer att anonymiseras så att ingen individ kan identifieras. När examensarbetet är färdigt kommer det att finnas i en databas vid Göteborgs Universitet.

Deltagandet är helt frivilligt och du kan när som helst avbryta din medverkan utan närmare motivering.

Om du är intresserad av att delta i studien eller har frågor så kan du kontakta mig via: guslidulo@student.gu.se

Lovisa Lidung
Master's student in Gendering Practices
The Department of Cultural Sciences at University of Gothenburg

Attachment 2. Interview Questions

Hur gammal är du och när fick du din endometriosdiagnos? (om diagnos är ställd) - *frågan ställs för att veta hur resterande frågor ska formuleras*

När hade du ditt första möte med vården pga. symtom kopplade till endometrios?

- Hur blev du bemött av vårdpersonalen?
- Hur ledde det fram till diagnos/utredning om diagnos, hur många år tog det?
- Upplevde du någon förändring från vården när du fick en diagnos?/ Tror du att det skulle vara någon skillnad om du fick en diagnos?
- Hur upplever du vårdens kunskapsnivå?
- Hur var din uppfattning om vården innan dina endometriossymtom uppkom?
- Hur är den nu efter?

Vilka professioner har du mött inom vården pga din endometrios?

- Hur upplever du skillnaderna kring kunskap?
- Hur upplever du skillnader kring bemötande?

Hur upplever du vårdpersonalens bemötande av dig som endometriospatient?

- Hur upplever du att vården förhåller sig kring fördomar om endometrios?
- Hur planeras din behandling (om du har någon)? Tas dina åsikter i åtanke?
- Hur har du blivit bemött av vården när du har sökt vård som inte gäller symtom som är kopplade till endometrios?

Har du några särskilda upplevelser som har befast sig specifikt i mötet med vården som endometriospatient?

- Hur känner du dig inför ett möte med vården?
- Hur ser dina förberedelser ut inför ett vårdmöte? - Hade du upplevt det annorlunda om vårdmötet skulle handla om något som inte berör endometrios?
- Anpassar du hur du ser ut, klär dig, sättet du talar eller dina reaktioner under vårdmötet? - Om ja, varför tror du att du gör det? Upplever du att det gör någon skillnad?

Hur såg ditt sämsta vårdmöte ut?

- Vad är det som gör att det sticker ut från dina andra upplevelser?
- Anmälde du händelsen? - Om svar ja, vad blev utfallet?
- Vad tycker du hade kunnat göras annorlunda?

Hur såg ditt bästa vårdmöte ut?

- Vad var det som gjorde att det stack ut från andra upplevelser?
- Hur skulle ett vårdmöte ur ett drömscenario se ut?

Hur upplever du makatrelataion mellan dig och vården?

- Vad tror du att vården har för uppfattning om sin egna makt, *ex. är de medvetna om att den existerar, utnyttjar de den eller motarbetar de den?*

Hur mycket kontroll upplever du att du har över ditt sjukdomsförlopp?

- Hur upplever du att vården förhåller sig till dina åsikter om din kropp?

Avslutande, är det något mer du vill tillägga som vi inte har pratat om?