

# Endometriosis – an undone science



Bachelor thesis in sociology

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## **Abstract**

Endometriosis is a disease that affects many but is known by few. Because of its relation to uterus and the menstrual cycle, it is often labeled as a gendered condition, or a woman's disease. The growing media attention around the ignorance of women's diseases in society has gained much attention lately, and there has also been a growing interest in studying the inequalities within women's diseases in the medical field. However, considering endometriosis is a gendered condition, it is also relevant to study endometriosis through a sociological lens, which I have chosen to do in this thesis. More specifically, I will study sociological literature on endometriosis through a feminist gender perspective, using insights from sociology of health. This study seeks to investigate the gendered meanings ascribed in endometriosis literature and their impact on research, as well as how these meanings have evolved over time. The literature review spans from the 1940s to present day. By approaching endometriosis through a sociological lens, this study aims to contribute to the growing body of knowledge on gender inequalities in health and provide insight into the role of gender in the understanding and management of endometriosis.

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## Introduction

Through the last few months, I have talked to many people about what I will be writing my bachelor's thesis about. When I tell people that I want to study endometriosis, I have received many different reactions, but the most common reaction is "OK... what is that?"

An endometriosis association from the UK called "Endometriosis UK" has found that 54 percent of people in the UK do not know what endometriosis is. However, amongst men, this statistic rises to 74 percent (Endometriosis UK, 2020). In the same study, they find that 1.5 million people in the UK are affected by endometriosis, which is similar to the amount of people affected by asthma or diabetes (Endometriosis UK, 2020). These statistics mirror the traditions seen across the Western world. This lack of awareness and knowledge about endometriosis is a concern that motivates the research proposed in this thesis.

Additionally, in Norway, there has been much focus around women's health in the past year, especially after the rapport on the inequalities on women's health in the medical and health field was published in March of 2023 (Norges Offentlige Utredninger, 2023). In response, the Norwegian media has covered women's diseases or generally diseases that affect the uterus extensively, including endometriosis. These articles have explained what endometriosis is and interviewed at least one person suffering from endometriosis, who then explains what it is like to live with the disease (VG, 2023; Berntsen & Fjelldalen, 2023). By reading these articles over the past year, while also having friends who have endometriosis, I started asking myself; why have I not heard more about this disease earlier? And why has it received so little attention and research, considering it affects approximately 1 in 10 women (World Health Organization, 2021)? Then, I started wondering if gender had anything to do with this. This is my motivation for choosing to analyze endometriosis through a feminist gender perspective.

I have chosen to conduct a literature review as my method of research. I wish to analyze literature on endometriosis through a feminist gender perspective and analyze the gendered perception of the disease in the various literature. In addition, I will also use insights from sociology of health to help me understand endometriosis from a sociological viewpoint. Sociology of health will, for instance, help me examine what role gender has played in the health field and how this has affected the understanding of endometriosis. My research

question is therefore: *How can we understand sociological research on endometriosis through a feminist gender perspective?*

To help me answer this question, my analysis will be guided by a number of analytical questions; *How has endometriosis been understood in research literature over time? What meanings are ascribed to gender in the literature? And how do the understandings of gender and endometriosis change from earlier literature and throughout the more recent literature?*

## **Endometriosis – context**

To understand what I will be analyzing in this paper, I wish to contextualize endometriosis and describe how it affects both the patients and society. Therefore, in this chapter, I will summarize what kind of illness endometriosis is, how many it affects, its symptoms, the diagnosis process, and the treatment process. Also, I will make the connection to how society's norms affect the understanding of endometriosis. Endometriosis is, according to social scientist Kate Seear, a “thoroughly gendered and highly stigmatized condition, one that is negotiated around the meanings of blood, menstruation, pain, fertility and infertility” (Seear, 2014, p. 6) and this is one of the main points I wish to examine in my analysis.

### **Endometriosis as a medical issue**

Endometriosis was first researched by Karl Freiherr von Rokitansky in the 1860s, but the condition was not given its name until John Sampson started calling it endometriosis in 1925 (Derman, 2004). World Health Organization explains endometriosis as a “disease where tissue similar to the lining of the uterus grows outside the uterus, causing pain and/or infertility.” (World Health Organization, 2021) The symptoms vary from person to person but may include a combination of the following: painful menstrual period, chronic pelvic pain, lower back pain, excessive bleeding during menstruation, pain during and/or after sexual intercourse, painful bowel movements, painful urination, fatigue, depression or anxiety, abdominal bloating and nausea, and infertility (World Health Organization, 2021; Lang, 2022). It is believed that endometriosis affects anywhere between 5 to 15 percent of all women, and an estimated 30-50 percent of all who are affected by endometriosis are infertile (Seear, 2014; Denny, Women's experience of endometriosis, 2003; Moen, Majak, Ringen, &

Veddeng, 2021). (The statistics, however, does not mention if this covers all people with a uterus, or only cis women.) Despite this, there has not yet been found a treatment that is completely safe and that eliminates recurrence (Seear, 2014).

The treatment to endometriosis includes pain relief, oral contraception, and other hormonal agents with harmful side effects (Denny, Women's experience of endometriosis, 2003). These treatments have a focus of relieving the patient of the painful symptoms, or to put a stop to the monthly menstruation cycle since this is when the symptoms are at their worst. However, this treatment method is not suitable for persons who wish to get pregnant, since they affect ovulation (World Health Organization, 2021). Another alternative of treatment is to remove the tissue, lesions and adhesions. To remove these, surgery is the only available method. The success rate varies, and the lesions have a 20 to 40 percent chance of recurring even after successful eradication (Endometriosis.net, 2018). Many also need surgical laparoscopic visualization to get the diagnosis, or to get a confirmation of the extent of disease (World Health Organization, 2021). The process to get this surgery done is long and complicated.

### **Endometriosis as a societal issue**

Endometriosis also have many consequences in society. Endometriosis goes hand in hand with menstrual problems, and this makes it difficult for many people to talk about their struggles if they are experiencing symptoms of endometriosis. Menstruation is a subject that many find taboo to talk about. In a study from 1996, it was discovered that the average time for a person to get the official diagnosis of endometriosis is 7.96 years in the United Kingdom, and 11.73 years in the United States of America (Seear, 2009) Today, the average in Norway is still at least 5 years (Norges Offentlige Utredninger, 2023). Plan International did research on over 4000 men and boys in the Netherlands, Brazil, Indonesia and Uganda, where 1 of 3 respondents meant that menstruation should be kept a secret, and around 40 percent associated menstruation as something repulsive (Plan International, n.d.). Because of this shame put on people who menstruate, they are scared to talk about menstrual related problems. This may be one of the reasons why the diagnosis delay is so large in the whole world (Denny, 2003). In addition, people often experience that health professionals do not take their problems seriously when they come to them with menstrual problems (Denny, 2003). This is possibly a contributing reason to why endometriosis has not gotten much attention in science; it is often brushed off as something everyone who menstruates have to

deal with (Denny, 2003). Endometriosis also affects the patients' everyday life in a large degree, sometimes making it difficult for them to attend school or work (Berntsen & Fjellidalen, 2023) or causing issues in their sexual health because of the pains (World Health Organization, 2021).

## **Methodology**

As my method of research, I have decided to conduct a literature review. This means that I will be looking into the literature that already exists on my topic and perform my analysis based on this. I will be performing a semi-structured review. The aim of a semi-structured review is to create an overview of a topic, and to look at how the research in a selected field has progressed and developed over time (Snyder, 2019).

### **Why I chose a literature review**

Selecting this methodology in this study is premised on several factors. Firstly, the extant literature on endometriosis, particularly in the field of sociology, is comparatively scant. An examination of the results yielded by a Google Scholar search using the terms "endometriosis sociology" reveals only 11,500 entries, whereas a search of only the term "endometriosis" results in 452,000 entries. Given the gendered nature of the condition, it is apparent that societal perceptions of gender may have a profound impact on endometriosis, making it relevant to study within sociology. Therefore, I wish to study sociological literature on endometriosis. Secondly, I want to investigate what researchers within sociology have researched about the topic, what perspectives they use and the conclusions they have reached. Given the growing body of information around endometriosis over the past few decades, and it is interesting to look at how it has developed over the years. Thirdly, I seek to explore the

gendered nature of endometriosis and the potential impact this may have conducted on its research. I will therefore use feminist gender perspective to conduct my analysis. As endometriosis is commonly perceived as a woman's disease, the study aims to investigate whether such perceptions may have influenced the understanding of endometriosis and its research.

### **The research process**

The literature I have looked for in this process includes literature that covers sociology of endometriosis, sociology of health, gender theory, feminist theory and gender perspective. To identify this literature, I have used search engines such as Oriano and Google Scholar. I used terms such as "endometriosis", "sociology endometriosis", "endometriosis gender", "gender theory", "feminist theory", "gender and health", "women's health", "sociology of health", "feminist theory" and other combinations of these words and phrases. My literature contains a mix of books and research articles.

In my research process, I also made the decision to rule out all medical literature on the topic. As endometriosis is a medical condition, most of the research done on the topic is conducted within the medical field. However, as such research was not relevant to my thesis, the selection of relevant literature necessitated a meticulous and refined process. Medical research was solely used to reference to factual information about endometriosis as a disease. The initial search for literature on the topic was centered on Norwegian literature; however, I soon discovered that the topic has been extensively researched in English. Therefore, I decided to continue looking for literature written in English rather than in Norwegian. The decision to write the paper in English was also influenced by the fact that the majority of relevant literature was in English. All my literature also has a focus on the western world, with most research coming from the U.S., the U.K. and Norway.

### **Advantages and disadvantages to a literature review**

Undertaking a literature study presents both advantages and disadvantages. One advantage is that it enables researchers to base their study on thorough and peer reviewed science, allowing them to generate new knowledge in their field based on previous research. It also allows researchers to get a good overview of the existing knowledge on the topic, as well as its

limitations and deficiencies (University of Illinois, 2022). This overview also facilitates the identification of new and unexplored areas in your field and allows you to identify research gaps (Snyder, 2019). A thorough review of the existing literature on a particular topic exposes researchers to a wide range of knowledge, including diverse research focuses previously explored by other researchers. The use of varied methodologies in previous studies also ensures that the findings are comprehensive.

One of the disadvantages of conducting a literature review is the time-consuming nature of this method. To conduct a thorough review of the literature, researchers need to read and comprehend a significant amount of research and literature, analyze the texts, and synthesize the results to draw their conclusions. Additionally, in some cases, certain topics may lack empirical research. This could be due to a variety of reasons. In the case of my study, it could be due to insufficient funding for research or the limited exploration of medical conditions from a sociological perspective, as in the case of endometriosis. Lastly, you have to be critical in your approach to literature. Researchers must be cautious of potential bias, as we will see exemplified in my thesis. Science and literature can in many ways be used as a tool of power. The criteria on how to produce science is constantly changing.

## **Theory**

In order to provide a sociological understanding of endometriosis, this thesis adopts two theoretical perspectives from the field of sociology as a basis of the analysis: feminist gender perspective and sociology of health. The feminist gender perspective is utilized to examine the impact of gender on the literature related to endometriosis and to assess the ways in which this has shaped the understanding of the disease. Additionally, insights from sociology of health are employed to analyze endometriosis as a medical condition from a sociological standpoint and to explore potential reasons why the disease has not received extensive attention in the medical field, and to explore potential factors that may have influenced the research on endometriosis, including the role of gender. Ultimately, these theoretical perspectives allow for a comprehensive and nuanced analysis of the sociological factors that have contributed to the current state of research on endometriosis.

## **Sociological Feminist Perspectives on Gender**

Sociological research and theories had the same limitations as the majority of other sciences had when it became a field of research in the 19<sup>th</sup> and 20<sup>th</sup> century; it was largely based on the perspectives of white, heterosexual men (Aakvaag, 2008). However, from the mid 1900s and onwards, scientists started realizing that by basing their science on these perspectives, they were erasing the lives of people of color, queer people, and of women within science. This is when they started creating new theoretical traditions, basing them on the voices and perspectives of “the others” (Aakvaag, 2008).

Feminist theory is based on two main points, according to sociologist Gunnar Aakvaag. The first point is that society is organized as a patriarchy. Patriarchy is a system where men have a higher social status than women, and where men hold power. This means that society’s institutions are designed to favor men when it comes to distribution of, for instance, power, status, money, and freedom (Aakvaag, 2008). This is based on a gender hierarchy that society has been built upon. The second main point in feminist theory is that most “objective” science actually just describes society through men’s perspectives and on men’s premises (Aakvaag, 2008). Because of this, science is contributing to upholding the patriarchy, making men the “normal” and women the deviation. This is why feminist theorists strive to make women visible in science and include women’s perspectives and premises when developing new theories, terms and empirical studies (Aakvaag, 2008).

When using gender perspectives, there are many ways to view gender. Most sociologists see gender as socially constructed (Korsvik & Rustad, 2018). However, sociologists have many theories on how gender is socially constructed; for instance, some understand gender as fluid, some describe it as performative and some understand gender as something you continuously do in everyday life (West & Zimmerman, 1987; Butler, 1990). I understand gender as tied to power and structures of inequality in our society, whether it affects women, men, trans people or non-binary people. To me, analyzing something through a gender perspective is looking at how gender is constructed and understood, how it influences the possibilities and privileges one has (or is deprived of) and how they are treated. When studying something with a gender perspective in research, many sociologists and feminist theorists separate between gender and sex. In this understanding, sex refers to anatomical differences such as reproductive organs,

chromosomes, genes, hormone levels, brain structure and muscle mass (Korsvik & Rustad, 2018). Gender, on the other hand, refers to the socially and culturally constructed norms, expectations and values to what it means to be a man or a woman (Korsvik & Rustad, 2018). Gender also refers to which actions and attitudes are defined as masculine and feminine (Korsvik & Rustad, 2018). By separating sex and gender, feminist theorists can show that society uses gender to organize gender roles that enables men to dominate women, and that it is not determined by biology (Aakvaag, 2008). This also lets feminist theorists show that everything that is socially constructed could have been done differently, there is nothing in biology that predestines men to be the dominant sex in society as a whole. Creating and upholding gender roles is also a way for a patriarchal society to put people into metaphorical boxes, and creating a separation between the genders (Korsvik & Rustad, 2018), as a way to uphold control and simultaneously creating a barrier for everyone who does not feel like they fit in the two “boxes” for the two genders.

### **Sociology of Health**

When conducting my analysis, I will combine a sociological feminist gender perspective with insights from sociology of health. Sociology of health as its own field within sociology was first developed in the 1950s when sociologist Talcott Parsons wrote about his work on sociology within medicine in his book *The Social System* (White, 2002). Throughout the next decades, it developed from being a field that looked at relationship between doctor and patient, to looking at much larger areas of research. Today, the sociology of health has several key concepts, according to sociologist Kevin White. “The sociology of health ranges over a wide territory: how some conditions come to be called diseases; the experience of being sick or ill; the organization of the medical profession; the ways in which health politics are produced; and the workings of hospitals.” (White, 2002, p. 39). Sociologists studying health often focus on how people’s position in society affect them when they get sick, their treatment, and how they die. Sociologists think that this is not only affected by biology or personality, but how the person is positioned in relation to class, gender and ethnicity (White, 2002). Another key element in the sociological perspectives on health is how someone is treated of their illness, or if they are treated, is not always a product of biological necessity, but of social control (White, 2002).

In the 1980s and onwards, sociologists studying health started looking at how patriarchal science has affected medicine and health. Feminist sociologists found that medical knowledge favors masculine interests in several ways, the main one being how women are distinguished from men in medical science. The key finding is how women often are excluded from research completely:

“An analysis of the articles published in the *Journal of the American Medical Association* between 1990 and 1992 found that women are under-represented in clinical trials. Among studies of non-gender-specific diseases, women were under-represented – excluded from, or were less than one-third of the subjects – in nearly three times as many studies as were men.

Many major tests of new drugs or treatments that do not include women in their sample population, even if the drugs are for use on women.” (White, 2002, p. 140)

The sociologists found that a middle-aged white man weighing around 70 kilos was the norm within medicine while women were looked at as difficult subject to include because of their menstrual cycle, or it was simply assumed that the drugs and treatments would affect them in the same way (Schei & Sundby, 2013). Women’s bodies were looked at as the “less complete” version of the man’s body (Norges Offentlige Utredninger, 2023, p. 56). Women were often seen as difficult because they complained about “non-existing illnesses”, and they were not taken seriously (Schei & Sundby, 2013). This is precisely why both sociology of health and a gender perspective is relevant for my paper.

## **Literature overview**

In this chapter, I will provide an overview of the relevant literature that forms the basis of my analysis. During my research, I observed that the major research on endometriosis with

sociological aspects could be separated into three different periods. Because of this, I have also sorted my literature into three time periods, the first being 1920s - 1950s, the second being the 1960s - 1990s, and the third being the 2000s. I chose to divide them into these three periods as there are certain characteristics and traditions that are found and shared in each period. This overview will consist of a brief review of the focuses the literature of the different periods had, and then I will look more into each period in depth and analyze the content of the literature in my analysis chapter.

To ensure a manageable amount of literature to analyze, I had to make strategic choices regarding which literature to include. I selected the literature that I believed best captured the general characteristics and traditions of each period and provided a comprehensive overview of the various focuses during these periods. While I could not include all the relevant literature I found, I believe that the selected works effectively represent the different periods and their respective focuses.

### **The first period – 1920s – 1950s**

The term “endometriosis” was first mentioned in literature in a paper by John Albertson Sampson in 1925, titled “Heterotopic or misplaced Endometrial Tissue” (Seear, 2014). Ever since the condition became a formal part of biomedicine, the research and its results has varied a lot. Endometriosis has always been a very complex and mysterious illness to research (Seear, 2014) and it still is to this day. In her book “The Makings of a Modern Epidemic” (2014), researcher Kate Seear looks at how several physicians researched endometriosis in the earliest period. She found that Joe Vincent Meigs was one of the first physicians to research endometriosis within medicine in the 1930s. Throughout the 1930s, 40s and 50s, he researched what endometriosis was, why it developed in women, but also why it appeared to be on the rise. In a paper Meigs wrote in 1941, he researched the demographic distribution of endometriosis patients and reached the conclusion that endometriosis was a “career-woman disease” (Seear, 2014, p. 6). He concluded that endometriosis was a disease “specific to white, well-educated patients” (Seear, 2014, p. 37). He alleged that endometriosis developed on women who waited to reproduce, and this was seen mostly among “women in the more successful, higher income group” (Seear, 2014, p. 37).

In the research from this time period, we observe the influence of misogynistic, racial and class focused traditions. Such research endeavors reinforced the exertion of control over women and their reproductive capacities.

### **The second period – 1960s – 1990s**

The next set of big claims Seear found about endometriosis came in the 1980s, when physicians started claiming that the disease had become an epidemic. In this period, a Canadian physician named James Campbell researched possible connections between endometriosis and chemicals in food. A few years later, Mary Lou Ballweg informed Campbell that there had been a previous similar study, where they possibly found a connection between endometriosis and a chemical toxin. The research was conducted on monkeys before the funding was cut. There have not been found any studies that can definitely link endometriosis with chemicals. However, these two developments alongside the notion of endometriosis becoming a disease with epidemic proportions, caused the hypotheses of the possible environmental and social causes of endometriosis to start rising. This happened after the women's movement in the 1970s, where women started demanding equality, and the women's health movement in the 1980s when women fought to take their place in academia and pursue more focus on women's health issues.

### **The third period – 2000s and forward**

This period consists of a much larger amount of literature on endometriosis than the previous two.

One of the main social scientists who studies endometriosis in this period is medical sociologist Nicky Hudson. Hudson examines how endometriosis has been examined in literature throughout history, or rather how it has not been examined. She sees endometriosis as an example of undone science because of how it has “remained so largely ignored in government policy and research funding globally” (Hudson, 2021, p. 20). For example, she looks at how there has been made links between endometriosis and historical descriptions of hysteria; behavioral disturbances that were believed to be caused by the uterus in early history may have been cases of undiagnosed endometriosis. This link has been made by several

authors because of how hysteria was a reason behind how women were constructed as unstable, gender deviant and unable to bear children (Hudson, 2021).

Hudson's paper on "undone science" is a good example of what the literature in the 2000s focused on. She acknowledges that the focus on endometriosis has not been good enough and how endometriosis became a result of political, cultural and structural processes and forces that privileged certain voices and communities while others fell behind (Hudson, 2021). This is the focus several sociologists have had while researching endometriosis in modern times; how did endometriosis fall behind and why is it important to give more attention to it.

Another common focus in modern literature on endometriosis is to study the diagnostic delay, and to look at why the average time to get the diagnosis of endometriosis is so long. For example, in her paper "The etiquette of endometriosis: Stigmatisation, menstrual concealment and the diagnostic delay" (2009), Kate Seear looks at how menstrual pains are stigmatized, and how this can result in people not wanting to go to their doctor about problems related to their menstrual cycle. She also asks whether doctors have normalized menstrual pains and excuses it as something everyone with menstrual cycles have to go through. Modern literature also focuses on experiences with endometriosis and wishes to illuminate how difficult it is to live with this condition (Denny, Women's experience of endometriosis, 2003). Today's literature has more of a focus on how the patients are affected by endometriosis and how it is to live with the disease. However, even today we continuously discover how women has been less prioritized in several fields, especially in medicine. The Norwegian public investigation (NOU) recently did research on what deficiencies exist in the medical field on women's health and made many valuable findings, for instance that women's health has a low status in the medical field, and the knowledge barrier between illnesses that mainly affect men and illnesses that mainly affect women is quite large (Norges Offentlige Utredninger, 2023).

During this contemporary period, which is ongoing, the focus has shifted towards the experiences of patients with endometriosis and how the disease affects their lives.

Researchers have demonstrated an increased interest in identifying ways to improve the quality of life for patients, as well as advocating for greater attention and recognition of the condition in medical and social contexts. This marks a significant departure from previous literature which had largely ignored the social and personal impact of endometriosis on patients and is a positive step towards improving care and support for those affected by the condition.

## **Analysis**

For my analysis, I will examine the distinct features and trends that delineate each time period and their impact on the endometriosis research literature. Additionally, I will incorporate a feminist gender perspective into each analytical section, in order to examine the ways in which gender biases and societal attitudes towards women have shaped the literature on endometriosis.

### **Analysis of the first period – a career-women’s disease**

As previously stated, the first period covers the 1920s – 1950s, which is the period when the first literature on endometriosis was published. In this period, John Albertson Samson and Joe Vincent Meigs were the leading physicians who conducted research on endometriosis. I will focus on Meigs’ research as it exhibits distinct characteristics.

In Meigs’ paper from 1941, where he proclaimed that endometriosis was a “career-women disease”, he also wrote about his central ideas about the disease, why he thought endometriosis was “spreading”, and how he thought this problem could be solved. The following citation is from Meigs’ 1941 paper:

“to the economic times we live in, and my plea is that patients with apparent infertility, evidences of underdevelopment and older girls about to be married, be taught how to become pregnant and not how to avoid pregnancy, even though their finances are limited. The monkey mates as soon as she becomes of age, and has offspring until she can no longer have any or until she dies. Menstruation in this animal must be rare. As women have the same physiology it must be wrong to put off child-bearing until 14 to 20 years of menstrual life have passed”

(Meigs, 1941, p. 869)

He follows up this idea in a paper in 1948:

“In nature certainly early child-bearing and frequent child-bearing is the usual thing. This may be prevented by some untoward circumstances, such as caging and domestication. Certainly some monkeys who menstruate, as women do, mate early following the menarche and have offspring, nurse, and then become pregnant again. In their natural habitat, they probably follow this sequence until they either physiologically can have no more offspring or die. This is what nature expects of animals. The human being does not carry out nature’s rules. Our grandmothers and great grandmothers probably more nearly approximated the ways of nature than the modern women, at least up to World War II.” (Meigs, 1948, p. 798)

In these quotes, we see Meigs explaining what he believed to be the best solution to the problem that is endometriosis. By his reference to menstruation and “apparent infertility”, we can interpret that Meigs did not see endometriosis as the comprehensive disease it is, but rather solely as a condition that stopped women from getting pregnant. His proposed solution was that women should continuously get pregnant, thereby avoiding the period of menstruation during which the symptoms of endometriosis are most severe (World Health Organization, 2021). Moreover, Meigs did not acknowledge the women who were entirely infertile due to endometriosis and instead suggested that they be “taught how to become pregnant”. This limited perspective on the disease reveals a misogynistic view of women that was prevalent during his era.

In addition to not acknowledging the entirety of the disease, he also goes on to compare women to monkeys. This also exemplifies the very misogynistic traits of this period. Women were frequently reduced into the roles as mother, caretaker, and reproducer. Meigs did not see women’s careers and their potential to contribute to the economy as important factors, despite the economic difficulties in that period. He viewed women in the same way as animals who’s main role was to reproduce as much as physically possible, or until they die (Seear, 2014). Reading with a feminist gender perspective with insights from sociology of health, we can see how Meigs, as a professional physician, used his research in a way that controlled the women. Also, by concentrating only on reproduction rather than the disease itself and how it impacted the patients, Meigs employed biomedical science to enforce patriarchal notions on women and reproduction. His literature reflects misogynistic views on women. This also serves as an

example of how literature and research can be linked to power structures, in this case in the form of patriarchal notions on women and reproduction.

Meigs also wrote about how endometriosis was “less common amongst ‘less well-to-do patients’” and one of his main concerns was that these less well-to-do people would eventually “out-produce” those of higher social status (Seear, 2014, p. 37). In one of his papers, he wrote recommendations to doctors concerning his worries about reproduction. He wrote “It would seem from this that we must encourage our own families and our more successful patients and their families to marry earlier, and when they are married, to have children.” (Seear, 2014, p. 37) He also stated that endometriosis was a disease that specifically affected white, well-educated patients (Seear, 2014). The use of the phrase “our own” indicates a reference to the upper classes. This implies that rather than being concerned of the illness itself and its patients, Meigs prioritized the fertility and reproduction of individuals belonging to the white middle class. This again exemplifies how research was employed to maintain social control by asserting that white people of a higher social class must remain the majority of the population.

In this period, we see how endometriosis was categorized as a gendered condition in the earliest literature. The research conducted focused on attributing endometriosis as a result of women’s life choices, consequently utilizing the disease as a means of controlling women. By placing the blame on women’s choices of lifestyle, the research reinforced patriarchal values and promoted motherhood and reproduction as the optimal solution. The comparison of women to animals that ought to continuously reproduce, the research illustrates the extent to which the disease’s impact on women was not prioritized, but rather their infertility. Meigs’ research can be said to have been used as a method to uphold a patriarchal structure, where women were supposed to be mothers and caregivers and were not supposed to become economically independent and self-sufficient. Moreover, as seen through the view of sociology of health, Meigs’ research served as a method of power and control, ultimately obstructing patients from receiving appropriate medical assistance for endometriosis. Instead of encouraging medical professionals and doctors to find a cure for the disease, he instructed them to “teach” women how to become pregnant. A feminist gender perspective highlights how this period was dominated by traditional patriarchal characteristics, where the primary concern was how women would uphold their roles as mother and caregiver, and this was then viewed as a solution to endometriosis.

### **Analysis of the second period – the environmental hypothesis**

The next period expands over the 1960s to the 1990s. In this period, the focus of research on endometriosis sees significant changes. The biggest findings come in the 1980s, when physicians James Campbell and Mary Lou Ballweg studied the connection between toxins in food and endometriosis. Campbell was first with his research on the link between endometriosis and polychlorinated biphenyls, or PCBs, in food but the study generated little interest (Seear, 2014). A few years later, Ballweg contacted Campbell to inform him about a previous study. This study was conducted on monkeys, where the monkeys were exposed to high concentrations of a chemical called dioxin (Seear, 2014). This resulted in two of the monkeys dying, and upon further examination they discovered that they had developed severe endometriosis (Seear, 2014). However, the funding to the research had been exhausted, so Ballweg reached out to those involved and provided an urgent funding so the findings could be published. The research concluded that “dioxins and PCBs affect the body’s immune system in ways that restrict the woman’s capacity to fight off wayward endometrial tissue.” (Seear, 2014, p. 39). To date, there is no certain link between chemicals and pollutants in the environment and endometriosis, and this study published by Ballweg remains controversial (Seear, 2014). However, from this study, researchers opened up more to the idea of the environmental changes possibly affecting the apparent rise of endometriosis cases.

This new insight of possible causes to endometriosis cases was an important change in the research on the disease. As we have seen, in the first period, researchers blamed women for developing endometriosis and used this to focus on women’s ability to reproduce and claimed that reproduction and motherhood were the best solutions to stop the disease. However, with the environmental hypothesis, women and their bodies were no longer the only to blame. Social scientist Stella Capek discusses how this is a development that now locates causality in the “social body”, not just the individual body of a woman (Capek, 2000). This contributes to relocating moral blame, by linking bodies to new developments in the environment rather than focusing all blame at “selfish” choices made by career-women (Capek, 2000).

During this period of research, there was a significant shift in the understanding of endometriosis, as it was no longer solely attributed to women's life choices. Although there were no solid findings on whether or not endometriosis could actually be affected by the environment and chemicals in food, this period opened up new possibilities for research into the environmental and chemical factors that may contribute to the development of the disease. However, this progress was not without its challenges. The publication of the Ballweg study was only made possible through donations from the Endometriosis Association when the funding for the previous researchers was exhausted (Seear, 2014). This highlights the underfunding and lack of prioritization of women's health issues. Women's health has always been of lower status in the medical field, and diseases affecting only or mostly women is at the bottom of the hierarchy of prioritized diseases in the western world (Norges Offentlige Utredninger, 2023). In this period of research, we can see this being exemplified when funding on endometriosis research was exhausted and needed the help of volunteers to become published. This is compounded by the male-dominated medical field (Norges Offentlige Utredninger, 2023). Furthermore, in the 1980s, the importance of the gender aspect in academic fields gained attention, causing women to form the so-called "women's-health guerilla" in the western world (Norges Offentlige Utredninger, 2023) and more women joined academia and the medical field. The rise of the women's health movement and the increasing presence of women in academia and medicine have led to greater recognition and focus on diseases that predominantly affect women. This has been a turning point for the sociology of health for women, as they have gained better opportunities for fair and equitable treatment through increased attention to the diseases that primarily impact them.

Adopting a feminist gender perspective allows for a more nuanced understanding of the developments in the study of endometriosis during this period. The recognition of the gendered aspect of health was a significant achievement in the advancement of research on women's health. It was crucial to broaden the focus of research beyond a universal body-type and consider other variables that may influence the development of endometriosis. This move away from blaming women for their illness was a crucial step towards a more inclusive and holistic approach to research on endometriosis. Moreover, this approach facilitated a more generalizable science on the condition, free from power dynamics and patriarchal structures.

### **Analysis of the third period – stigmatization and undone science**

The third period of endometriosis literature is ongoing and may be identified as commencing around 2000. The quantity of literature on endometriosis in this period has increased significantly, providing an opportunity for a more comprehensive investigation of the topic. The shift in focus from the previous periods is noteworthy, as the current period places greater emphasis on the experiences of endometriosis patients and their quality of life, with a view to improving the lives of all those affected by the condition. Additionally, several sociologists have turned their attention to understanding why endometriosis has received little attention in the medical field and wider society, and why diagnosis is often significantly delayed (Seear, 2009; Hudson, 2021; Lang, 2022). Such inquiries recognize the need to address not only the medical aspects of the condition but also the societal and cultural factors that impact it.

Medical sociologist Nicky Hudson categorizes endometriosis as a “missed disease” and an example of “undone science” in her 2021 paper where she investigates how may have occurred. She argues that endometriosis has been disregarded by research funding and in government policies, and that it falls under a pattern of structural, political and cultural processes that continuously chooses to undermine the importance of knowledge about endometriosis (Hudson, 2021). She calls it “willful ignorance” because it has been inhibited by underinvestment in scientific research despite endometriosis affecting more people in the UK than diabetes (Hudson, 2021). Hudson discusses how conditions such as diabetes and asthma have similar social and economic burdens, yet they remain a public health priority in first-world context, while endometriosis continues to get underfunded and ignored. This results in ongoing omissions in the knowledge of endometriosis, its etiology and symptomology, and how it affects the lives of the patients as well as families and society (Hudson, 2021). Hudson links this neglect to the fact that most endometriosis patients experience not being believed by their healthcare professionals or in primary care due to the lack of knowledge on the condition. People also do not feel comfortable talking about their symptoms of endometriosis to their general practitioner. There may be many reasons to this, but some claim that it’s uncomfortable because it involves such intimate parts of their private lives, such as the menses or pain during intercourse, or because they are afraid not to be believed (Hudson, 2021). This is especially relevant in the cases of minoritized people.

Evidence shows that people of color, especially women of color, tend to be treated as “less reliable narrators” compared to white women when they speak about pain-related issues to clinicians (Denny, Culley, Papadopoulos, & Apenteng, 2010; Hudson, 2021). This issue may be a factor in the long diagnostic delay associated with endometriosis, as patients may be underestimated or too ashamed to be fully transparent with their healthcare provider (Hudson, 2021).

Hudson also looks at other ways that endometriosis has been systematically ignored earlier in history too. She for instance ties the historical description of hysteria as a possible misdiagnosis of endometriosis. She explains this by looking at how other authors have explored how endometriosis and hysteria share several common sociohistorical discourses. Hysteria was often diagnosed when a woman describes problems with pelvic pain, inability to bear children and other behavioral disturbances that were believed to be caused by the uterus (Hudson, 2021). However, there is no precise evidence of this connection. Although, hysteria was a much-used diagnosis in the earliest of history, subjecting women to murder, madhouses and other methods that caused women to live in physical, social and psychological pain (Hudson, 2021). Hudson connects these issues with the ongoing issues that many endometriosis patients struggle with being believed about pain-related symptoms, and how this has been an issue for most of history. She uses polycystic ovary syndrome (POS), fibromyalgia and migraines as other examples of conditions where pain is one of the main symptoms among women, and that also have been systemically dismissed or ignored alongside endometriosis.

The issue of being embarrassed or ashamed to talk to healthcare professionals about endometriosis symptoms is also a topic for many when researching the social side of endometriosis in this period. This issue can be related to endometriosis’ connection to menstruation, and how menstruation has been stigmatized in society for a long time. This is one of the issues that Kate Seear looks into in her paper on “the etiquette of endometriosis”. Social scientist Erving Goffman defined stigma as a “deeply discrediting and socially undesirable attribute” (Seear, 2009, p. 1222) and said that people who possess these deeply discrediting attributes are often stigmatized, indicating that they are weak, bad or dangerous (Goffman, 1963). These attributes can differ from different cultures and historical periods, but they can involve attributes such as physical deformities, blemishes of character and tribal stigma (Goffman, 1963). Goffman also defined differences that are not immediately apparent

to those you interact with, calling these “discreditable individuals” (Goffman, 1963). People who menstruate fall under this category, and several studies show that people who menstruate feel the need to keep their menstruation a secret, and as something embarrassing because they view their menstrual cycle as something negative and shameful (Seear, 2009). Through this, she analyzes the etiquette of endometriosis. By “etiquette”, she means that menstruation and endometriosis is considered taboo, and it enforces people’s behavior by fear of social sanctions, such as being ridiculed for their symptoms (Seear, 2009). People are enforced to hiding everything that has to do with their menstrual cycle in fear of how people around them will react to it. Seear interviews several women about their experiences with how people reacts when menses is brought up, discussing how the women were often encouraged to conceal their menstruation, by for example using and disposing of sanitary wear without detection, or not being believed when speaking about their pains (Seear, 2009).

In the third period of literature, marked by significant changes compared to the previous two, there has been a notable shift in the patriarchal power imbalance in the medical field, as indicated by insights from sociology of health. Diseases that predominantly affect women have gained increased attention in various fields, including medical, social and in media. A rapport on women’s health in 2023 by the Norwegian government, the first assessment on women’s health done since 1999, highlighted the profound inequalities surrounding women’s health and the low priority given to women’s health research. Amongst many other issues, it looked at endometriosis and its related issues (Norges Offentlige Utredninger, 2023). It discussed how we can improve the patient’s lives both medically and socially and gave several recommendations on how to achieve this, for instance by giving measures to shorten diagnostic delays. Furthermore, endometriosis has received significant media attention, which has raised public awareness of the condition and highlighted the need for improvements in the medical care and knowledge (VG, 2023; Bermtsen & Fjelldalen, 2023). This increased attention helps to normalize discussions about endometriosis and may encourage patients to speak more openly with their healthcare professionals. Also, by promoting attention to endometriosis in the medical field, it opens up more opportunities for research and improvement of knowledge about the condition, which can ultimately lead to healthcare professionals being able to provide better help for the patients.

The literature pertaining to this period recognizes the importance of gender in the comprehension of endometriosis on multiple fronts. Firstly, it delves into the way women’s

health has been relegated to the periphery of medical research over time, and how endometriosis has been a casualty of this neglect. For instance, NOU's report on inequalities in women's health states that the Norwegian national directorate of health has no professional guidelines on knowledge-based practice and exercise of service on endometriosis and that this is a common issue with typical women's diseases (Norges Offentlige Utredninger, 2023, p. 58). This is because of the lack of research, experiences from practice, and the patients' own wishes and needs (Norges Offentlige Utredninger, 2023). The literature further demonstrates how earlier research have selectively emphasized certain voices while disregarding others, with diseases to women typically being overlooked or given low priority (Hudson, 2021) and how men have long controlled which diseases are prioritized (Norges Offentlige Utredninger, 2023). This has led to inadequate information on endometriosis among medical practitioners, making it difficult to diagnose and furthermore contributing to a long diagnostic delay.

Secondly, the literature highlights the impact of the stigma surrounding menstrual problems. This can be perceived as a gendered issue considering that many people connect the menstrual cycle to women. The notion that menstruation should be concealed to avoid social sanctions resulted in many patients finding it difficult to discuss their menstrual problems and their endometriosis symptoms with their medical professionals, thereby exacerbating the long diagnostic delay associated with endometriosis. Additionally, patients suffering from diseases with low prestige in the health field often experience stigmatization due to its lack of visibility (Norges Offentlige Utredninger, 2023). This leads me to the last aspect; by the use of media, this period employs the media to cast light on endometriosis alongside other gendered conditions to expose the insufficient knowledge on gendered illnesses, particularly those linked to women (VG, 2023; Berntsen & Fjellidalen, 2023). The literature in this period comprehends endometriosis as a gendered condition, and the literature emphasizes the deleterious impact of low prioritization, stigma and diagnostic delays. Furthermore, it emphasizes the need to change these trends through greater public awareness of endometriosis, which can be achieved through various means, including media and published research.

## **Discussion – across the three periods**

The literature on endometriosis has changed greatly from the first period to the third. I will therefore use this chapter to discuss the literature across the three periods in order to analyze the developments and changes.

The literature on endometriosis reflects the changing meanings of the concept of gender and its centrality in society. For each period, we can see how gender is being used less as a power tool and more as a tool to understand the disease. The first period of research on endometriosis coincided with a societal norm that placed women in the role of a stay-at-home housewife and caregiver, while the men were the family's provider (Westad Stuen, 2021). As such, the literature from this period reflects these patriarchal norms. For example, with Meigs, who sought a treatment for endometriosis that would not interfere with women's ability to fulfill their roles as mothers and caregivers. He claimed that women who tried to develop a career before getting children were more likely to develop endometriosis. This reflected the patriarchal norms of the 1940s-1950s (Westad Stuen, 2021).

In addition, with the rise of the feminist movement in the 1970s (Westad Stuen, 2021) and the women's-health-guerilla was formed in the 1980's (Norges Offentlige Utredninger, 2023), there was a growing recognition of the systemic factors that contributed to women's health issues, including endometriosis. This shift in perspective is evident in the literature on endometriosis during the second period, where the focus shifted away from blaming women and their choices, towards understanding the societal and environmental factors that contribute to the disease. As women became more visible in academic fields and in advocating for their own health, they were able to exert more influence on the research agenda and methodologies used to study endometriosis (Norges Offentlige Utredninger, 2023). This period of research reflected a changing attitude towards women's rights and health, with endometriosis being understood as a product of the social context in which it emerged, rather than an individual affliction caused by women's personal choices.

Lastly, the use of gender as a tool of power has been abandoned in the literature in the third period. Instead, scholars are examining the historical role this usage of gender played and its outcomes. The traditional view on women as being primarily mothers and caregivers is no

longer the central focus. The focus today is to acknowledge how endometriosis was systemically ignored or overlooked from research for decades. There is also a strong emphasis on expanding the research on endometriosis and improving the treatment and quality of life for those affected. From this, endometriosis can be said to be a reflection on society's perspective on women and the progress of women's rights in the Western world. In the years to come, we can hope to see the research on endometriosis continue to expand, and we can hope to see the recommendations outlined in the report on inequalities in women's health with regards to endometriosis be implemented (Norges Offentlige Utredninger, 2023).

In addition to there being a growing attention on endometriosis in research, there is also a growing attention around it in the media. The patients suffering from endometriosis is now also coming forward with their experiences with endometriosis, which can be a result of endometriosis becoming less stigmatized. These patients are then also able to contribute to creating a new focus around endometriosis and a more holistic understanding of the disease. This shift has been an important development, as previous research predominantly focused on finding the cause for endometriosis, rather than taking into account the patient's experiences. However, from hearing the experiences of endometriosis patients, we better understand the complexity of the disease. The media has played an essential role in raising awareness of endometriosis, making it a less stigmatized disease, and encouraging patients to share their stories. This has been crucial in increasing the understanding of the complexity of the disease, including the significant impact it has on the patients' quality of life. The media has also played a role in removing the taboo surrounding women's reproductive health issues, which have historically been stigmatized and misunderstood, as evidenced by the prevalence of diagnoses such as hysteria (Hudson, 2021). As a result, the media's attention to endometriosis has played a crucial role in both increasing public awareness and understanding of the disease, as well as contributing to ending the stigmatization of uterus-related health problems.

## **Conclusion**

The objective of this thesis was to gain a deeper understanding of endometriosis and its history by studying literature on endometriosis through a sociological feminist gender perspective with insights from sociology of health. From its earliest literature, we have seen

how endometriosis was understood as a gendered condition. Initially, endometriosis was perceived as a disease that obstructed women from getting children early on. It was believed that the best treatment for endometriosis was to continuously bear children. The gynecologist Joe Vincent Meigs blamed endometriosis on the life choices of women, indicating how women who opted for careers typically postponed childbirth, leading to endometriosis. Meigs' recommendation was that women should emulate monkeys by reproducing from an early age until they could no longer bear children, thereby avoiding menstruation and minimizing the effects of endometriosis.

Furthermore, the focus of endometriosis research has changed over time. After women started getting more power in the academic field in the 1980s, they started exploring other possible aspects that could cause endometriosis, absolving women's bodies and their choices from blame. Researchers have come to understand the interconnectedness between the environment and the body, and not only what choices the women make for themselves. Lastly, we see where the literature on endometriosis is today. The research is currently more focused on finding effective treatments for the disease. However, there is still no treatment that both allows the patients to become pregnant while being unaffected by endometriosis. Moreover, the diagnostic delay today is still 5-7 years in the western world (Norges Offentlige Utredninger, 2023; World Health Organization, 2021). As a result, contemporary literature is devoted to highlighting how women's health concerns and diseases have been systemically disregarded and stigmatized for decades and how such attitudes are being challenged and changed.

Adopting a feminist gender perspective, this study analyzes the development and evolution of gender perceptions in the literature across three time periods and compares them to the status of women's rights in society. Sociology of health is also employed to reveal how endometriosis exemplifies a disease that was dismissed under patriarchal science. The illness was not taken seriously for a long time, much because the patients were not believed, as the sociology of health highlights the patriarchal issues in the health field (Schei & Sundby, 2013). In addition, it is important to acknowledge the need for intersectional perspectives in studying health. As society moves away from a binary understanding of gender, it is crucial to consider how gender identity and expression may impact experiences of illness and health care. This is particularly relevant for endometriosis, where existing literature has focused primarily on cisgender women.

Furthermore, as the complexity of endometriosis becomes more apparent, there is a need for more thorough research on the disease. While current literature has primarily focused on the general understanding of endometriosis, there have been cases where the disease has spread to unexpected areas such as the lungs (Waalder, 2023). This highlights the need for future research to consider all aspects of the disease and examine it more comprehensively. Therefore, I believe the future of endometriosis research will have to consider the large complexity of this illness and will have to study it more thoroughly and examine all aspects.

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