



Gendered Knowledge in the Medical World and its Implications for Women with Endometriosis

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Abstract

Research in the medical world is gendered in a way that it has primarily focussed on masculine bodies, neglecting female bodies. The implications of this gender-biased knowledge are that to this day, more knowledge is available about masculine bodies as they were considered the norm due to the simplistic makeup compared to women's hormones and organs. This lack of knowledge about female bodies complicates women's experiences in receiving adequate healthcare as they are not believed since there is a knowledge gap in their symptoms. Recently this has been termed as medical gaslighting. Medical gaslighting becomes evident in diagnoses of endometriosis as this chronic disease is under-researched and underdiagnosed. Symptoms are dismissed as menstrual pain, complicating the procedure of receiving a diagnosis. Four women who have received an endometriosis diagnosis have been interviewed about their experiences of medical gaslighting during the diagnosis procedures. Additionally, a systematic literature review about gender-biased medical knowledge and medical gaslighting was conducted to analyse existing research. The data was thematically analysed in light of theories of coloniality, gender and ontological politics. Conclusions show that all four women experienced medical gaslighting which violently oppresses them by restricting them from receiving proper healthcare.

Keywords: gender-bias, medical knowledge, medical gaslighting, endometriosis

Introduction

Gender bias in the medical world stems, in part, from the lack of research conducted on female bodies (Verdonk et al., 2009). Masculine bodies were considered the norm in research and thus female bodies were excluded from vital research. It was believed that the female uterus was the cause of female health issues such as hysteria (Dinsdale & Crespi, 2017). This is a global issue that efforts around the world are aiming to alleviate. At the beginning of the 1990s, the United States National Institute of Health (NIH) formed a policy that made the inclusion of women and minorities in clinical research mandatory (NIH, n.d.). This means that research on female bodies is hundreds of years behind. Still today the standardized body in the medical world is that of a man, complicating diagnoses, and treatments for women.

When looking at gender bias from a sociological perspective, there are implications for women in medical practices. There is a culture of disbelief in women's symptoms as pain is normalized and trivialized (Grundström et al., 2018). Due to the implicit idea that women are overly emotional and irrational which relates to early conceptions of hysteria, their complaints

are often not taken seriously and dismissed (Dinsdale & Crespi, 2017). This is called medical gaslighting (Migala, 2022). Migala defines medical gaslighting as “when healthcare professional dismisses, invalidates or belittles a patient’s concerns or symptoms” (Migala, 2022, p. 57). It occurs when doctors tell women that their symptoms are not serious and hence do not further investigate. As knowledge is gendered through masculine normativity in the medical world, women’s experiences are often not believed if they do not fit the masculine narrative. Particularly within endometriosis, women experience a great amount of disbelief when explaining their levels of pain. Endometriosis is a condition only found in female bodies; however, it is assumed that the gendering of medical knowledge has implications within this field. As abnormal amounts of menstrual pain are the primary symptom women seek out medical advice for, the subjectivity associated with pain among genders has an impact on the diagnoses process (Grundström et al., 2018). Although endometriosis is found in around 10 per cent of women, it is underdiagnosed and ignored leaving many women suffering without knowing the reasons for their pain (Grundström et al., 2018). The following research question was answered through this research.

Research question: How does gender-biased medical knowledge influence women’s experience with medical gaslighting during their endometriosis diagnosis?

Endometriosis diagnoses have increasingly become a public issue. At the beginning of the year 2022, French President Macron announced the launch of a national plan to raise awareness of endometriosis, as well as improve diagnoses and treatments (Thompson, 2022). Macron states that “it is not only women’s problem, it’s society’s problem” (Thompson, 2022). This movement can be seen internationally as more women are speaking up about their experiences with having to convince health professionals of their symptoms. A woman with the Instagram username @endomindset said that she had to wait 11 years for a diagnosis as doctors repeatedly told her that menstrual pain was normal and that she was overreacting. This is largely discussed on social media, particularly by social media influencers as they have a large audience that they can be a support system for. When searching the #endometriosis, posts of women with lesser followings show up who also share their experience or who show support for other women. The more women openly discuss their experiences with getting a medical diagnosis, the more awareness of the culture of disbelief is spread.

Invisibility of Pain and Medical Gaslighting

Pain is considered to be subjective, with some people being better able to manage it than others (Johnston, Oprescu & Gray, 2015). To make pain visible, patients are often asked to explain their pain through a lived experience perspective and how it impacts their daily life (Johnston et al., 2015). Showing the implications that pain has can make it visible to others. When patients explain their pain, there often is disbelief and invisibility of pain through stigma, isolation, and emotional distress (Johnston et al., 2015). Originally gaslighting is a psychological term, however, recently sociologists (Migala, 2022; Sebring, 2021) have adopted this term in the medical world, hence, medical gaslighting. Medical gaslighting is when patients encounter invalidation, dismissal of their complaints and inadequate care to relieve them from their symptoms when there is no physical evidence of symptoms, such as pain (Sebring, 2021). Medical gaslighting affects and complicated the lives of women, transgender, queer, intersex, and racialized persons as they do not fit in the dominant masculine narrative of medical knowledge (Sebring, 2021).

This insight is useful for the implications of diagnosing endometriosis as initial diagnosis often starts with pain complaints. If these are not taken seriously, the diagnosis cannot proceed further (Grundström et al., 2018). Currently, pain caused by endometriosis must become visible in order for women to be taken seriously, creating a theatrical performance of pain. Women should not have to perform or convince health professionals of their symptoms, but all too often they must.

Endometriosis

Research conducted by Grundström et al. (2017) is the first to qualitatively investigate women's experiences with healthcare professionals regarding endometriosis. In-depth interviews were conducted to gain insight into healthcare professionals' and women's experiences with each other. The first finding was that women were being treated with ignorance, disbelief, and lack of knowledge. They felt as though they had exaggerated their symptoms or worried that they simply had a low pain tolerance. Women felt like they had to convince healthcare professionals of their symptoms. As the main symptom of endometriosis is pain, it is relative to every individual. Particularly women who encountered male healthcare professionals felt like they were not being believed. Though not all encounters were negative, creating a double-edged experience (Grundström et al., 2017).

With these theoretical approaches, there is a scientifically sound base for answering the research question. Research on gender bias in the medical world acknowledges that this is an issue that is not discussed enough (Verdonk et al., 2009). There is research about the diagnoses of endometriosis, however, it does not have a theoretical background. When linking gendered medical knowledge to the diagnosis of endometriosis, it functions as a possible theoretical explanation.

Relevance

Although there is no cure for endometriosis, there are therapies to help women cope with the symptoms, particularly the extreme pain, meaning that a diagnosis is highly important. It can help some women with their emotional distress by not feeling alone and feeling more legitimized. By researching this topic through conversations with women, this issue can be brought to the public and the shortcomings of the medical world can become pronounced. Women's experiences with feeling ignored are made known which can help with the public articulation of this issue.

Theoretical Framework

Coloniality of Knowledge

Decolonial studies offer a systemic theoretical perspective of the role power plays in a certain field. The main aspect of this framework is about the coloniality of knowledge production. The coloniality of knowledge makes knowledge production rigid and perpetuates power (Bhambra, 2014). It is extractive as it takes value from one thing to produce another authoritatively. It is important to acknowledge that knowledge production is happening in larger contexts with specific reasons behind them (Bhambra, 2014). These contexts can be seen as infrastructures that encourage dominant perspectives to be heard and others to remain unheard. The infrastructure in which knowledge is produced is gendered within the medical world, following the dominant masculine narrative (Bhambra, 2014). It is important to note that originally this framework looks at historical racial power dynamics which are also problematized in this field. Though looking at different forms of power, such as gender, paves the way for understanding how knowledge in the medical world is to be viewed and within what context it is produced. Coloniality theorises that colonialism is an ongoing process that causes domination in the political and social realm (Lugones, 2016). There are intersectional race and gender histories that to this day have implications on social and political power relationships. Particularly the normativity of the white male body creates power dynamics in the production of medical

knowledge (Bhambra, 2014). Due to this normativity, gender power dynamics are important to analyse. Knowledge is not one-sided as it can be understood differently based on methods and society and how it engages with it. This goes against the demarcationist view that assumes science is separate from society (Resnik, 2000). Instead, it is valuable to look at knowledge and its production in light of society and gendered power dynamics.

By extracting the power imbalance within coloniality of knowledge as a theoretical framework, power dynamics in the medical world due to gender can be uncovered. It makes visible that knowledge about masculine bodies has played a more important role than knowledge about female bodies. This creates gendered knowledge as there is a power imbalance and authoritative knowledge production focused on masculine bodies. Looking at how knowledge has been produced in medical history explains the development of this imbalance. Additionally, the anti-demarcationist perspective shows how knowledge production is still viewed today and within what infrastructure (Resnik, 2000). If knowledge production is demarcated from society, it can perpetuate the power imbalance as women's symptoms are not heard. There must be more dialogue between society and science which can be done by making this issue public (Resnik, 2000). By voicing women's experience of gender bias, more awareness and hopefully acknowledgement of the medical world can occur. This research is viewed from a coloniality of knowledge perspective to interpret how medical knowledge is gendered.

Gender in the Medical World

The categorisation of gender has a long-standing history and contemporary implications. As a theoretical basis for this research, gender must be theorised. Particularly, how gender is understood in the medical world is important for the analysis of the implications this has. According to Code's (1991) feminist epistemology, gender is situated in the production of knowledge. She acknowledges the significance that gender plays in who is 'the knower'. Gender can influence the doctor-patient relationship as there is a hierarchy and power imbalance (Code, 1991). This highlights the importance of not being 'gender blind' as it does influence patients' experiences and knowledge production. Foucault's *The Birth of the Clinic* (1989) additionally describes the medical gaze and how medical knowledge produced by healthcare professionals is often privileged over patients' experiences. Gender can influence the perception that healthcare professionals have of the validity of patients' experiences as the rigid knowledge seems more credible (Foucault, 1989). Understanding the importance of

gender in the medical world is needed to place women's experiences with being diagnosed with endometriosis as it influences both the patient and doctor.

Moreover, Katz, Seaman, and Diamond (2008) discuss how gender bias in the medical world perpetually oppresses women, particularly during diagnostics. They state that this began with the problematisation of the uterus, as has been stated earlier. Here, male and female bodies were clearly distinguished as normal and not, respectively. The standard of what a healthy body was, was based on that of a masculine one (Morris, 1991). Although it is often believed that the days of hysteria diagnoses are over, the term has been replaced by diagnoses of 'dissociative' and 'emotional'. This enforces violence toward women and furthers the gender bias of medical research (Katz et al., 2008). Although this article focuses on hysteria, the effects that gender has on diagnoses are highly relevant. It exposes the institutional oppression of women as the standardised medical body is masculine. This framework is useful to understand how gender and gender bias can be understood in the medical world.

Lastly, Verdonk et al. (2009) discuss how there is gender blindness in the medical world. Differences are ignored even when they are relevant. However, they also claim that medicine is male-biased for the same reason as the previous article. As historically more knowledge has been produced based on masculine bodies it harms diagnoses and treatments of female bodies. Lastly, they claim that gender inequality in the medical world has been ignored (Verdonk et al., 2009). The assumption that women and men are similar in health determinants is false, which is why gender bias has not been largely recognised. It impacts the health of men and women as resources are not allocated efficiently. What this article offers that is most important for this research is the conceptualisation of gender bias, namely: gender blindness, male bias, gender role ideology and gender inequality (Verdonk et al., 2009). Knowledge in the medical world focuses on masculine bodies unless it concerns reproduction health, where research on female bodies prevails (Verdonk et al., 2009). This male bias has implications for how knowledge is produced and applied. Hence, these conceptions of gender bias can be used to analyse how knowledge production in the medical world is gendered.

Ontological Politics

The ontological politics perspective states that there are different realities of lived experiences that are performed in different practices (Mol, 1998). These different realities co-exist and are implicated in the political present and enable to view the world from different standpoints. Realities are multiple, meaning that there are multiple ways of seeing, experiencing, or

practising a reality (Law & Urry, 2004). This means that there are multiple forms or versions of reality that can be performed and made actual (Mol, 1998). By using this framework, the way that endometriosis is performed in multiple ways is important to investigate in case the performativity changes during the diagnosis procedure. Women may feel confident that they have endometriosis before the diagnosis but when being not believed by healthcare professionals, endometriosis may be performed in a doubtful and uncertain way. Seeing the changes in lived realities of endometriosis helps understand the internal changes that women experience. Endometriosis can be performed in multiple ways for a woman which is why every experience and story is shared is important to understand the phenomenon.

Within this framework, the concept of agency in the style of politics is important to note. There are choices people can make as Mol explains through the example of medical interventions of anaemia. Either, patients can represent themselves as a citizen or a customer (Mol, 1998). Though underlying either of these realities is that to understand how patients are represented within practices of knowledge (Law & Urry, 2004). When applying this to the field of endometriosis, seeing how patients perform themselves in a reality is important to know whether they have agency in the style of politics or not. If patients are not believed and excused, this could limit their agency in how they represent themselves. Hence noting any changes in how endometriosis is performed during the diagnosis can indicate whether women feel like they have agency or not.

Methodology

Data Collection

It is important to note that every methodological choice has specific reasons and consequences. Remaining answerable to these choices is necessary to be an accountable researcher (Haraway, 1988). Within this section, the reasons, choices, and intent of the methodology are explained.

This research followed a two-step approach. Firstly, a systematic literature review (seen in Appendix A) of scientific articles was conducted for an overview of existing research about this topic (Bryman, 2012). This provided a foundation for the interviews about knowledge production in the medical world and medical gaslighting. The effects of gendered knowledge in the medical world are not only present in endometriosis diagnoses which is why the literature review covered a broader range of the medical and social fields. This places the case of endometriosis into the larger context of knowledge production in the medical world.

For the systematic literature review, the search terms “gendered” and “medical knowledge” yielded 154 results in Libraries Worldwide in the EUR library portal. When selecting results that are held by Erasmus University Rotterdam for accessibility, 78 results remained. No date limit parameters were set as the history of gendered knowledge was of interest. Out of these results, 15 sources were of relevance. The same steps were taken for the search term “medical gaslighting”. This yielded two texts that were used in the systematic literature review. Once the texts were selected, they were systematically analysed based on the issue it was thematising, the objective of the research and most importantly the keywords/phrases that were either provided by the author or that have been extracted after reading the text. This was completed in an Excel spreadsheet.

The second part of the methodology answered the research question by looking at the individual experiences of women with endometriosis. From the insights of the systematic literature review, an interview guide (seen in Appendix B) was created to build the semi-structured interviews that were conducted with women who have been diagnosed with endometriosis. Basing the interview questions on the systematic literature review raises the construct validity of this research (Bryman, 2012). Keywords from the systematic literature review were taken and incorporated into general interview question themes. The keywords extracted from the scientific articles ensured that the right questions were asked to answer the research question. Four interviews were conducted, and the interviews lasted between 40 and 70 minutes.

Sampling Method

A snowball sampling method was used to contact possible interviewees (Bryman, 2012). There is often a community of people who share their experiences, so by infiltrating one of these communities, one can gain access to several people who might be open to being interviewed. This community was German-speaking as there was an endometriosis movement happening called ‘EndoMarch’ which was a month dedicated to endometriosis. It happened that during March I was starting to reach out to women which was an unplanned benefit. This however limits the scope of interviewees that I reached as it was only German-speaking women. To create racial diversity, women of colour were contacted as well. However, no response was received which made my sample racially homogenous which is a notable limitation of this research. The search for interviewees started through Instagram accounts of influencers or mental coaches that focus their content on endometriosis. Instagram has a feature where it shows related accounts, creating a snowball sampling method. By following some of these

accounts, more get suggested which builds the community. A private message or email is then sent to these accounts in which I introduce myself and the intent of this research. I asked if they would be willing to partake in online interviews where they can talk about their experiences with endometriosis and what the diagnosis procedure was for them. I also ensured that the interviews would be anonymous to protect their privacy. Once they responded to my message, I provided them with a timeline of the research to give an indication of when the interviews would be conducted. One account posted my message on her story so that all her followers could see it and reach out to me. This meant that not only influencers were interviewed but also private people who followed the account.

Once the interviewees had been contacted and the interview dates were set up, the semi-structured interviews could commence which allowed for a more in-depth insight into their experiences and their thoughts about why they have experienced certain experiences (Bryman, 2012). The interviews were conducted over Zoom where the audio and video were recorded with the consent of the interviewees.

Analysis

To analyse the interviews, a thematic analysis was conducted (Braun & Clarke, 2006). A thematic analysis allows for a detailed and nuanced analysis of data which is suitable for smaller amounts of data to avoid over generalisations. This is a flexible approach that reveals themes across data as well as detailed accounts of specific aspects. Both the audio, more specifically the content, and the visual of the interview were analysed. The content contains the experiences and opinions of the women, whereas the visual video provides implicit insight into emotions and body language. Therefore, an essentialist/realist approach was used to analyse the data as it theorises individual experiences and meaning rather than generalising group experiences (Braun & Clarke, 2006). The recordings of the interviews were played back while taking notes about themes relating to the theoretical framework and the literature review. These notes were then colour coded based on the theoretical themes. Bottom-up topics per theme were then derived during the analysis. Differences between the women's experiences were also noted down to acknowledge the plurality of experiences and what might have caused these.

Operationalisation

To ensure construct validity, the operationalisation of the terms that are analysed is based on the key terms in the research question (Bryman, 2012). These key terms are 'gender-biased

medical knowledge’, ‘medical gaslighting, and ‘endometriosis diagnosis’. These terms were then used as search terms for the systematic literature review. Gender biased medical knowledge is thematised in a large body of literature and is accepted as a phenomenon. This was measured in the systematic literature review by touching on some of that body of literature. Gendered medical knowledge was also measured in the interviews by asking why they think they experienced medical gaslighting. This measures the reversed relationship between gender-biased medical knowledge and medical gaslighting

Medical gaslighting was measured by asking women if they felt that they were not believed, downplayed, or dismissed during their doctor visits. These questions were based on Sebring’s (2021) and Migala’s (2022) definitions of medical gaslighting. They state that medical gaslighting can be detected by invalidation, dismissal, and belittling of a patient’s concerns (Sebring, 2021; Migala, 2022).

Lastly, an endometriosis diagnosis was measured by a confirmed laparoscopic diagnosis. This is the most common procedure to diagnose endometriosis as the endometriotic cysts become visible. The difficulty of receiving the diagnosis was measured in the interviews by asking how many doctors they went to, how many years a diagnosis took and what challenges they had to face during the process.

Ethical and Privacy Considerations

Before the interviews proceeded, the interviewees were informed about the intent of this research to avoid manipulation. As the interviews provided insight into their health history and personal experiences, they must be treated with anonymity. The interviewees provided both written and verbal consent to the interview and the recording of it. The data was saved in a Google Drive folder so that it could not be found on the researchers laptop and will be deleted once the research is completed. The data generated from the interviews was not used for other purposes without the consent of the research subject (Babbie, 2016). Additionally, the anonymity of their healthcare professionals was ensured to protect their privacy and not harm their reputation.

As the interviewees recalled personal information, some were emotional during the interviews. When this happened, the researcher gave them time and space and offered to pause the interview. They were told that the interview could be terminated at any point if they no longer felt comfortable.

Findings and Data Analysis

Analysis of systematic literature review

In total 23 texts were analysed in the systematic literature review. This amounted to 129 keywords/phrases. Figure 1 is a word cloud which provides a visual representation of the keywords. The larger the word is, the more frequently it came up in the texts. The 11 most common keywords/phrases were: gender, women, chronic pain, medicine, body, gender bias, medical gaslighting, medicalisation, hysteria, and patient experience. The texts were heterogeneous as they discussed different medical topics and fields. Some topics were about the medical gaze, patient blaming, sick leave and chronic pain. This shows that gender-biased medical knowledge production does not only affect endometriosis patients but is a larger issue in the medical world. Additionally, the research methods varied from quantitative surveys to qualitative interviews to critiques and reviews.

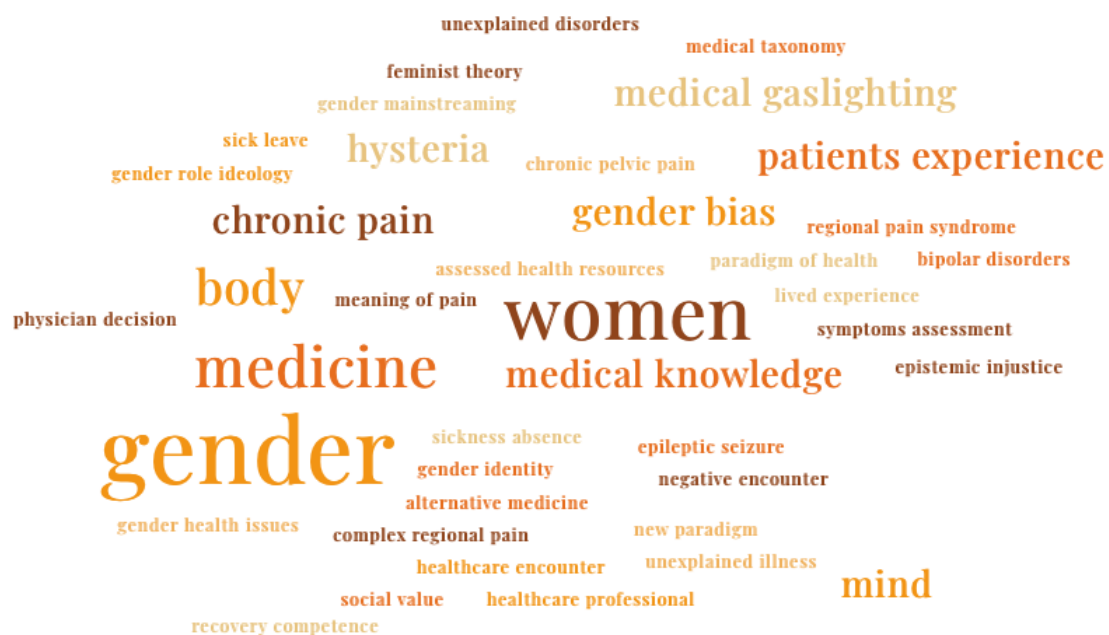


Figure 1: Word cloud of keywords

The overall narrative of the scientific articles will be explained in light of the theory presented in the theoretical framework. The general narrative was that gender is overlooked in medical practices which disadvantage women. Gender in the medical world is overlooked as there is a lack of specific knowledge about female bodies and health. Code's (1991) feminist epistemology states that gender is positioned in knowledge production and is important to acknowledge differences between genders. If generalisations are made, differences are

overseen, and the minority group is disadvantaged. Whether this is by disempowering them (Malterud & Hollnagel, 1999), oppressing women (Katz, Seaman & Diamond, 2008), or normalising their pain (Werner & Malterud, 2005), the lack of knowledge about female bodies still has implications to this day. The lack of knowledge about female bodies can be understood through the coloniality of (medical) knowledge (Bhambra, 2014). It is a form of oppression as male health and medical knowledge is prioritised over that of females. The power imbalance between health care professionals and patients reinforces this oppression as patients often feel helpless and lay compared to their doctors. Similarities with demarcationism are prevalent as the patient feels like the lay society reaching out to the expert doctors to help them (Resnik, 2000). This is a severe disadvantage to women as their health suffers from colonial medical knowledge production. Symptoms can be overlooked or not known, restricting women from seeking out and receiving the healthcare they require.

Gender has an impact on knowledge production in the medical world as masculine bodies and values have been considered the norm, which is called andronormativity which is particularly relevant in light of the normativity of the white male body creating power dynamics in the production of medical knowledge (Hølge-Hazelton & Malterud, 2009). This can be taken one step further as not only the medical knowledge production oppresses women, but the practice of medicine further disadvantages women. As Foucault (1989) claimed, doctors rarely admit to flaws of their practice and instead blame the patient. Doctors try to see patients as human beings without gender, but this perpetuates the issue as women's issues are not only disregarded in the medical world, but also purposely turned a blind eye to (Hølge-Hazelton & Malterud, 2009). Gender-blindness does not solve gender bias, it is a form of gender bias (Verdonk et al., 2009) Verdonk et al. (2009) claim that this is a form of violence against women because they do not receive adequate or precise healthcare. If men and women are treated indifferently, biological differences are overseen (Upmark, Borg & Alexanderson, 2007). When looking at this from a sociological perspective, societies' gender biases and stereotypes play a role in the medical world. As Sebring (2021) and Migala (2022) have proposed, medical gaslighting disempowers women and makes them feel helpless. As gender stereotypes display women as weak, emotional, and hypersensitive, symptoms such as pain are downplayed. Social gender stereotypes influence the medical knowledge production and practice as women are gaslit, either because there is a lack of knowledge about their symptoms, or because they are not believed to be severe enough to call for action (Sebring, 2021; Migala, 2022).

The lack of understanding between female patients and doctors leaves women feeling misunderstood and not taken seriously, and ultimately gaslit (Malterud, Candib & Code, 2004).

The status quo of medical knowledge is prioritized over patients' voices as this creates uncertainty (Malterud, Candib & Code, 2004). What became evident in the literature review is that when women don't receive the help that they are seeking out from healthcare professionals, some turn to alternative medicine. However, in doing so they risk receiving inadequate and non-scientific healthcare. Their physical health is being jeopardized in order for them to feel understood and listened to (Malterud, Candib & Code, 2004). The gaps in medical knowledge about female bodies are filled by alternative medicine which provides women with a sense of security as they no longer feel gaslit. This shows a serious fault in the medical world as it is gendered (Bhambra, 2014).

Analysis of interviews

Gendered coloniality of medical knowledge

The three theories from the theoretical framework guide the analysis of the interviews. Firstly, the coloniality of knowledge which is seen through a lack of knowledge about female bodies and the role of gender in the medical world through the phenomenon of medical gaslighting was analysed. Then an additional analytical layer provided by ontological politics contrasts the two previous theoretical perspectives as it assumes endometriosis is multiple and not underlying meaning medical gaslighting cannot be detected. However, this has political and practical consequences. The analysis is guided by anonymised quotes taken from the interviews that have been translated from German into English.

Lack of knowledge

All four women began their endometriosis journey not knowing what endometriosis was. When they started showing common symptoms such as irritable bowels, extreme menstrual pain or feeling faint, they sought out medical help as they did not know what caused these symptoms. When the women talked to their mothers, they were told that they experienced the same pain when they were younger and that is it normal. Doctors would prescribe them painkillers to manage the symptoms but did not further investigate the cause of them. One of the women, Isabelle, said that she would cry every time she left the doctor's office because all they did was prescribe her pain medicine which stopped working for her. She said, "nobody came up with this idea, nobody. And I didn't want to justify myself anymore". By saying "anymore" it is apparent that it happened multiple times meaning it is a common issue. It was always assumed that the pain was purely menstrual. When Isabelle did not get the answers she wanted, she went to five gynaecologists but none of them knew about endometriosis. Another woman, Sarah,

said that she always told her gynaecologists about her pain, but she never did anything about it. She even exaggerated a bit to try to make her believe her, even though it was already very bad pain. It didn't work so then she started crying to also show her how much pain she was in. Only then did the gynaecologists bring up endometriosis for the first time. She said that "it is not known among doctors, and it is a big problem". She did not receive any information about endometriosis, nor did her friends or family know what it was. She said that "the uncertainty about this disease is the worst thing". This quote means that the almost unbearable pain is not as bad as the mental strain that comes along with the disease. This mental strain and uncertainty are provided by healthcare professionals which are supposed to alleviate them but instead cause them due to gender-biased knowledge. There is limited information available given by your doctor, friends, and family or on the internet. The third woman, Tina, had similar experiences. She had extreme abdominal pain for which they conducted ultrasounds and laparoscopies, but they came back clear. Her doctor overlooked the endometriosis cysts in both tests which were later found by an endometriosis specialist. Carey, the last woman, said that she googled her symptoms and came across endometriosis this way for the first time. When she brought this up to her doctor, they said that endometriosis is a very rare disease and that her symptoms do not fit it. Instead, she was told that she had psychosomatic pain.

This shows a clear lack of knowledge about women's health because of gender-biased medical knowledge (Katz et al., 2008). There is a gendered nature in the medical world in which one can see structures of coloniality. The rigid gendered knowledge and lack of knowledge about female bodies stems from the gendered historical position in the medical world. When women portray clear symptoms of endometriosis, doctors assume other causalities that would be more probable. If more medical knowledge were available about women's health topics such as endometriosis, the symptoms could be detected earlier. Even when bringing up the suspicion of endometriosis they deny this as it is considered a rare disease rather than considering this option. Their doctors did not admit to the limitations of their knowledge gaps. Isabelle said, "They (the doctors) don't want to acknowledge that they don't know something so instead of acknowledging it, they keep believing that they are right and that the patient is wrong." This is what Foucault (1989) called the medical gaze, changing the patient's story to fit their own narrative. As there is a lack of knowledge about women's health, doctors create their own narrative to superficially fill the black box.

Normativity of masculine bodies

The women expressed their wishes that doctors would inform themselves about the disease prior to their appointment. Instead, they had to inform the doctors about what endometriosis was and then were often told that they are wrong about assuming that they had this disease. This rigid form of knowledge that does not adapt to new information given by the patient is colonial in nature. It only considers the dominant knowledge that is imposed on women. This can lightly be compared to the Indian residential school system in Canada from 1894 to 1947 (McQuaid et al., 2017). Imposing the Western culture and forced assimilation disregards the cultural practices of indigenous communities. Nuclear families were imposed on children which came along with a rigid focus on gender roles (McQuaid et al., 2017). Dismissing one and claiming precedence over the other is colonial (Bhambra, 2014). Similarly, although to a less severe degree, the gendered knowledge in the medical world can be seen as colonial. Knowledge about masculine bodies has precedence over female bodies and knowledge provided by female patients is disregarded.

The rigid structures of the coloniality of gendered medical knowledge shifted the focus of medical research onto the normativity of masculine bodies which makes women's health issues under-researched. Isabelle brought this up as she said, "women are too complicated because of our menstrual cycles and hormones". The normativity of a healthy human body disregards female hormone cycles similarly as women's uterus was assumed to be the cause of hysteria (Katz et al., 2008). Isabelle also said that "medicine is made for men only". The "only" means that medicine is made for men and is not applicable to women. Medicine is based on masculine bodies and does not take into consideration the differences between male and female bodies. Additionally, she said that "men's health issues are just better researched". She thinks that being a woman with medical needs is a big disadvantage because nobody cares about you or knows what could be wrong with your health. If masculine bodies are seen as the norm in the medical world, then women's differences such as menstrual cycles and hormones are not taken into consideration even though this greatly affects women's health (Bhambra, 2014). This is a form of violent oppression against women as their health is considered less worthy than that of men (Katz et al., 2008). This uncovers structures of coloniality as there is an intentional blind spot that overlooks what women have to say.

Reproductive health

The women brought up the topic of reproduction health. During their doctor appointments, the focus was always on their reproductive health rather than their health in general. Sarah was

told as a 21-year-old that she needed to have children now or else she would never be able to have children. She was advised to a fertility clinic before she even received a proper diagnosis. She said that unfortunately “endometriosis is a reproductive issue rather than a women’s health issue”. The fact that she said “rather” instead of “and” shows that a women’s health issue is automatically labelled as a reproductive issue. Women are seen as reproductive objects and if something threatens this ability then they are a medical concern. Even though having children was not a wish for Sarah, she was repeatedly told that she must have children now. Women are not seen as women aside from being potential mothers. Similarly, Tina explained that once she had decided on a hysterectomy, her doctors and nurses at different hospitals tried talking her out of it as she would regret not having children. They did not try to change her mind due to medical concerns, but purely out of subjective reproductive ideals. She said that “there is a lot of questioning, not only in hysterectomies, but in endometriosis in general. You are not respected”. Her choices about her body were not respected as she went against the ideal image of a woman being a child bearer. Carey also stated that she had no desire in being a biological mother as she is in a lesbian partnership where they both agreed not to raise children. She also decided on a hysterectomy and was questioned by her doctors about this decision. This made her feel even more insecure about accepting that she has a chronic disease, adding to her mental strain. Women being told that their health is only important if it concerns reproduction is of colonial nature. Imposing gender roles and teaching women the duty of reproduction even though they had accepted a different reality for themselves already is oppressive (Lugones, 2016). The coloniality of gender relations looks at both oppression and liberation of gender and race (Lugones, 2016). The imposition of gender roles is oppressive and prohibits liberation. In the cases of the women, they were still able to liberate and have control over their own bodies, but the attempt to change their minds for nonmedical reasons has traces of coloniality structures (Lugones, 2016).

Demarcationist hierarchy

Additionally, there is a power asymmetry between the doctor and patient which reinforced the coloniality of gendered knowledge (Code, 1991). The women expressed that they felt like their doctors had no time for them and did not want to listen to what they had to say. They did not take suggestions or listened to their experiences. Instead, the doctors were convinced that their prognosis was correct. The women were often intimated and in a frozen state during appointments. Isabelle said to avoid this she would bring notes to her appointments about the topic she wanted to mention and wouldn’t leave before she got answers. Sarah and Tina said

that when possible, during covid, they would bring their partners with them into appointments to speak up for them. The hierarchy between doctor and patient signifies the demarcationist perspective which relates to the coloniality of knowledge (Resnik, 2000). The patient is seen as the lay society who does not have the expert knowledge as the doctor apparently has. Even when the women showed agency and knowledge, the doctors refused to admit to their faults or limitations (Foucault, 1989). Tina said that “doctors are trying to impose their own opinion and their own image onto the patients, and they no longer hear what the patient is saying and what problems they have”. By saying “they no longer hear what the patient is saying” means that because they try to over voice the patient, they become mute to them. If the doctors did not try to impose their opinion and instead listened to the knowledge they are receiving from the patient, they would actually hear what the patient is saying. The knowledge production was demarcated from the patient even though it is about the patient. Typically, the demarcationist view has been applied to a macro view of society at large, but in these interviews, it became apparent that it happens on micro levels as well (Resnik, 2000). It happens in doctors’ offices more than we know. Doctors see themselves as the expert and produce knowledge *about* the lay patient *without* them. The gendered power asymmetry between men and women and doctor and patient which reflect the structures of coloniality and oppresses women medically as they cannot seek out the help they require.

Normalisation and invisibility of pain

These experiences show how normalization is a big issue in the medical world. Normalisation and medical gaslighting enhance each other as they downplay patients’ symptoms because there is a lack of knowledge. Normalisation often, therefore, occurs before medical gaslighting as patients are told that their symptoms are normal and that they are over exaggerating, hence dismissing them. If actual symptoms of a disease are considered normal due to the lack of knowledge about female bodies and female-only diseases, then there is no need to proceed with further tests and a diagnosis. It is also seen that gender bias plays a role in normalization and medical gaslighting as these women were told to not complain because they are a woman (Katz et al., 2008). They felt that because endometriosis is a women’s health issue, their pain is not believed as women are societally considered to be overly sensitive and dramatic. Isabelle said that “we, as women, are not seen and our diseases are dismissed” and that this is society’s fault.

Pain is not only normalised, but it is also invisible to an outsider (Johnston et al., 2015). Based on the accounts of the women, they were only started to be taken seriously if their pain

has other physical effects such as fainting or crying. Believing that someone is in pain is based on trust that the person is telling the truth as pain is invisible (Johnston et al., 2015). When there is low trust between doctors and patients, patients are often not believed when they are in pain, or that the pain is more severe than 'normal' levels. These women had to perform their pain in a way to make it visible to their doctors to be taken seriously as Sarah had specifically stated. However, this reinforces the gender stereotype of women's sensitivity. If they purely state that are experiencing extreme pain and are not believed, then they must make their symptoms visible and perform them differently through crying for example. But if a woman is crying in the doctor's office, she is then seen as overly sensitive and emotional. This is a destructive cycle that complicates women seeking medical help.

Experiences with medical gaslighting

The practical implication of the above-mentioned mechanisms is that women are medically gaslit when seeking an endometriosis diagnosis. The individual experiences with medical gaslighting were expressed in the interviews and will be presented in the following. Once Isabelle went to numerous doctors and endometriosis was found after the laparoscopy, she said she felt helpless and alone. People around her were telling her that she is exaggerating and looking for attention. She finally had an answer to all her questions, but she didn't feel like a human, instead "you just feel like a number to them". Evidentially a degree of automation is needed in healthcare, however, the fact that she said that you "just feel like a number" shows that she felt dehumanized. Depersonalisation has mental implications on the patient as they feel detached from themselves. The nurses in the hospital told her that they only found a small number of cysts and that her pain couldn't have been that bad. She had a lot of questions and concerns about her diagnosis, but she said that "the worries and fears are not taken seriously". She still experienced a great amount of pain, but they said they are only phantom pains and that she should just continue taking pain medicine. Even after having proof of her experiences through a medical diagnosis, she said that "one is just not believed". She didn't feel taken seriously before her diagnosis but once the diagnosis was found, she was sent off to cope with everything else on her own. When she was at home though, she stated that "feeling alone is the worst because my friends and family don't understand my experiences". The gaslighting continued at home as people simply did not understand what she was going through. The medical gaslighting changed into normal gaslighting at home as they did not understand her pain. She got teary eyes when explaining that she wished that people would have just asked her

how she is doing and that they would have genuinely listened to her. This would have helped her feel understood and not feel gaslight.

Similarly, Sarah said that her pain was never taken seriously as she is a highly sensitive person. She said that every day that she would complain about her stomach pain and that “nobody believes you anymore”. A difference in Sarah’s experience is that she believes that “they don't necessarily play it down, they just don't know what to do”. The word “necessarily” indicates that she thinks the gaslighting is not intentional even though it stems from intentional gender-biased knowledge. Sarah said that since she is a highly sensitive and shy person, it is her fault that she couldn’t convince her doctors of her symptoms early on. However, when looking at the definition of medical gaslighting, her self-blaming looks like an internalization of gaslighting (Sebring, 2021). She had been told numerous times that there was nothing wrong with her that she believed that it is her fault for being shy and not expressing herself enough. Here again, the hierarchy between doctor and patient can be seen as she doubts herself in the authority of a doctor (Code, 1991).

Tina experienced and acknowledged that she was medically gaslit during her search for a diagnosis. She thought her symptoms were normal because everyone told her “You’re just a woman, don't cry around like that” even though she would faint in class due to her pain. This led to her having to drop out of high school as her medical condition prohibited her from attending class. Her gynaecologist conducted ultrasounds and said everything was normal. When she went to an endometriosis specialist, he did the same and immediately said that what he sees is not normal. She said that when she went to the endometriosis specialist “I didn't know what to expect, wouldn't I be taken seriously again? I was through with gynaecologist because they didn't help me anyway. But he didn't look at me like I was lying to him when I told him about my pain”. This quote shows that her initial reaction to going to a new doctor is expecting to not be taken seriously as it has happened to her before. Two weeks later, with a laparoscopy, he diagnosed endometriosis and PCOS, confirming all her symptoms and taking her seriously.

Carey was in a wheelchair for three months because of extreme pain and she would lose sensation in her legs, causing her to faint. She was diagnosed with psychosomatic symptoms despite her clear symptoms. She said that “I wasn’t taken seriously at all”. Her doctors blamed all her symptoms on her mental health, which worsened her mental health as she felt alone, helpless, and not believed. She said that “you are convinced into thinking that you are the problem”. The fact that she said “you are convinced into thinking” instead of “they try to convince you into thinking” shows that medical gaslighting has real effects on the patient. The

manipulation works against the patient, and they start to believe what they are told. As she experienced extreme symptoms that prevented her from walking for three months, she really felt medically gaslit when they told her she just has psychological medical issues. Without looking for physical causes for her symptoms they said that everything she is experiencing is psychological. Carey wishes that she would have been treated differently and that she would have been believed by her doctors. She feels like she has lost years of her life that she can never get back.

Ontological politics

The ontological politics theory aids this analysis by looking at the changes in how endometriosis was performed throughout the diagnosis procedure (Mol, 1998). This theory adds a contrasting perspective about how endometriosis is multiple depending on the setups through which it becomes actual.

At the start of their medical journey, none of the women knew what endometriosis was as it was not well known. However, after hearing about endometriosis in some ways, they all were convinced that they had endometriosis as their symptoms aligned with this disease. They believed their symptoms that they are caused by endometriosis. Even without having received a diagnosis, they knew that their pain was not normal anymore. Their symptoms are performed in a confident way before they sought out help. Though as soon as they sought out medical help and were told that everything was normal this changed their own perception as well. Isabelle said that “then you doubt yourself because if you are told all the time, you have nothing, what you have is normal, then at some point you will believe it yourself and then it will be even harder to stand up for yourself and say no, that is the way I feel”. Her endometriosis symptoms were performed in a doubtful way (Mol, 1998). Tina similarly said that she had to convince herself to believe in her symptoms after her doctors would tell her that everything is normal. To not lose her self-respect, she had to remind herself that what she is feeling is valid and to continuously perform her symptoms in a confident way (Mol, 1998).

All four women started to doubt and question themselves while still trying to convince others of their symptoms during the appointments to make their lived experience of endometriosis actual. Isabelle went to self-help groups to improve her self-confidence about believing in her experiences after being medically gaslit, Sarah turned to alternative medicine to help her cope with her pain as she felt believed there, which in the systematic literature review was stated to be problematic, Tina turned to her friends and family for mental support and Carey turned to her psychologist to confirm that her pain was not psychosomatic

symptoms. Different settings and experiences can change the way the disease is performed, making it multiple.

The contrasting view that ontological politics introduces is that medical gaslighting would not be detected because of the multiple performativities of endometriosis. It would be incorrect to label a performativity of endometriosis as medical gaslighting. Instead, it would be seen as psychosomatic pain, just as Carey was told she has. However, by viewing endometriosis from this lens, we do precisely what has been criticized. Nevertheless, this perspective offers a valuable contrast as it looks at the performativity of endometriosis which cannot be labelled as anything else but multiple. It shows how it becomes actual whereas the previous theories showed how the actuality was restricted due to medical gaslighting. The ontological politics theory yields consequences that I reject to accept due to social and political implications that invalidate women. *Choosing* to see medical gaslighting brings value to understanding the colonial oppression of women due to gender-biased knowledge in the medical world.

Limitations and recommendations

This study has limitations that have implications for the generalisability of the findings. Most importantly, the sample size of only four respondents is a limitation to the generalisability. Even though the four women who were interviewed had very similar experiences, more women should be interviewed to solidify the theoretical standing of medical gaslighting. Additionally, the diversity of women was limited in terms of race. Only white women were interviewed who could have significantly different experiences than women of colour. It is highly important to further research their experiences as women of colour experience more discrimination and oppression than white women. Lastly, focussing on endometriosis only allowed for a more detailed analysis within the given time restrictions, however widening the scope beyond endometriosis could investigate whether women with other conditions where pain is not the main symptom, experience similar medical gaslighting. It is already known that the signs of a female heart attacks are often overlooked as they differ from men's symptoms (Dinsdale & Crespi, 2017). This would show how the gender-biased knowledge production has implications for all women.

Conclusion

The research question that was asked throughout was: how does gender biased-medical knowledge influence women's experience with medical gaslighting during their endometriosis diagnosis? It can be concluded that gender-biased medical knowledge causes a lack of

knowledge about female bodies and health amongst healthcare professionals which leads them to dismiss the concerns of their patients through normalising symptoms and refusing to admit to their own limitations. Particularly when a symptom is pain, it is invisible to an outsider until it is performed outwardly. Endometriosis is underdiagnosed as its main symptom, pain, is often normalised as menstrual pain as this health issue is under-researched. Women are medically gaslit when they explain that their symptoms are not normal menstrual symptoms. This medical gaslighting is due to the lack of knowledge about female bodies due to the normativity of masculine bodies in medical research. This has oppressive and violent implications for women as they do not receive adequate healthcare, often waiting years for a diagnosis. The traces of colonial structures are visible when compared to for example the Canadian indigenous residential school systems of imposing a culture onto another (McQuaid et al., 2017). The lack of agency and liberation over one's body is oppressive and colonial. Medical gaslighting has far-reaching implications as these women are not only dismissed and belittled by their healthcare professionals, but also by themselves over time. They lost their agency over their mind and body in trying to receive a diagnosis (Mol, 1998). They did not only lose their agency, but Isabelle and Sarah lost six years, Tina eight years and Carey seven years of their life waiting for a diagnosis.

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Appendix A – Systematic Literature Review

Author(s)	Year	Title	Document type	Journal	Database	Research	Issue	Objective	Keywords
Verdonk et al	2009	From gender bias to gender awareness in medical education	Article	Advances in Health Sciences Education	SpringerLink	Review	Lack of uptake of gender issues in medical education	Assist the integration of gender equity in medical schools	Equality, equity, gender bias, gender health issues, gender role ideology, gender mainstreaming, gender awareness, medical education
Grundström, Alehagen, Kjølhed & Carina	2018	The double-edged experience of healthcare encounters among women with endometriosis	Article	Journal of Clinical Nursing	Wiley Online Library	Qualitative	The experience with healthcare encounters affected the women's perceptions of themselves and of their bodies.	Shed light onto the experiences of healthcare encounters among women with endometriosis	Dysmenorrhoea, endometriosis, experience, healthcare encounter, healthcare professionals
Dinsdale & Crespi	2017	Revisiting the wandering womb: oxytocin in endometriosis and bipolar disorder	Article	Advances in Health Sciences Education	MEDLINE	Review	Elevated oxytocinergic system activity jointly contributes to bipolar disorder and endometriosis	Show how mind-body interactions, and the pleiotropic endocrine systems that underlie them, contribute to health and disease.	Oxytocin, Endometriosis, Bipolar disorder, Hysteria, Pleiotropy, Evolutionary medicine, Psychiatry, Mania, Hippocrates, Mind-body
Johnston, Oprescu & Gray	2015	Building the evidence for crps research from a lived experience perspective	Article	Scandinavian Journal of Pain	MEDLINE	Review	As pain is subjective, Complex Regional Pain Syndrome (CRPS) is difficult to diagnose and is often poorly managed.	To identify and synthesise the literature on experiences of living with chronic pain in order to understand where and how CRPS research may be best situated in the future.	Complex Regional Pain Syndrome (CRPS), Chronic pain, Lived experience, Patient experience, Caregivers
Katz, Seaman & Diamond	2008	Exposing Gender bias in medical taxonomy: toward embracing a gender difference without disenfranchising women	Article	Women's Health Issues	MEDLINE	Commentary	Gender bias perpetuates the oppression of women in medical taxonomy	Emphasizing the effect of gender bias on the very act of diagnosing.	Gender bias, medical taxonomy, hysteria, fibromyalgia, diagnoses, gender differences
Grace & MacBride-Stewart	2007	Gendered Meanings of Chronic Pelvic Pain	Article	Health 11	ArticleFirst	Qualitative interviews	Chronic pelvic pain in women has gendered meanings	how normalizing pain works within the narratives that women's pelvic pain as intrinsically gendered	chronic pelvic pain; meanings of pain; medicalization; normalization; women

Green	2006	An unhelpful neglect? Examining the relationship between child health and gender in research and policy	Article	Critical Social Policy	ArticleFirst	Qualitative policy analysis	Relationship between child health and gender has potential influence that gendered behavioural, cultural and psychological factors have on children's health	Bring attention to gender in the development and implementation of child health policy	children, illness, policy, sex differences
Malterud & Hollnagel	1999	Encouraging the strengths of women patients	Article	Scandinavian Journal of Public Health	ArticleFirst	Qualitative case study	The disempowering medicalization of women patients	how the use of empowering dialogues in general practice can contribute to alternative images of women	case study, coping, empowering, feminist theory, general practice, salutogenesis, self-assessed health resources, strengths, transcript, women.
Upmark, Borg & Alexanderson	2007	Gender differences in experiencing negative encounters with healthcare: A study of long-term sickness absentees	Article	Scandinavian Journal of Public Health	ArticleFirst	Quantitative survey	Both women and men were treated with indifference, with disrespect, that the professional did not take his/her time, did not listen, did not believe in, or doubted complaints	Analyse gender differences in sickness absentees' experiences of negative encounters with healthcare professionals	Gender, negative encounter, sickness absence, sick leave
Hølge-Hazelton & Malterud	2009	Gender in medicine - does it matter?	Article	Scandinavian Journal of Public Health	SAGE Journals	Qualitative theoretical analysis	Gender has a strong impact on medical knowledge and practice. The concept andronormativity means male values are regarded as normal and that female values disappear or need to be blatantly highlighted in order to be recognized.	Exploring the claim that doctors encounter their patients as human beings, not as men or women, and discuss causes and consequences of such a claim.	Gender, gender identity, medicine, men, prejudice, sex, women, andronormativity.
Welch, Lutfey, Gerstenberger & Grace	2012	Gendered Uncertainty and Variation in Physicians' Decisions for Coronary Heart Disease	Article	Journal of Health and Social Behaviour	Arts & Sciences I	Qualitative interviews	Physicians apply knowledge that women have "atypical symptoms" as a generalization, which engendered uncertainty for some	Examine how physicians' interpretations of patient sex-gender affect diagnostic certainty and decision making for coronary heart disease	disparities, gender, mixed methods, narrative analysis, physician decision making
Green	2008	Gendering the History of Women's Healthcare	Article	Gender & History	Wiley Online Library	Narrative	The influence of certain core narratives in the history of western women's healthcare	By seeing medical knowledge as a cultural product - something that is not static but continually re-created and sometimes contested - create an epistemology of how such knowledge is gendered in its genesis, dissemination and implementation.	Feminism, women's healthcare, Western influence, medical knowledge

Tomlinson	1999	Intensification and the Discourse of Decline: A Rhetoric of Medical Anthropology	Article	Medical Anthropology Quarterly	Arts & Sciences II	Review	Intensification shows that metaphors misrepresent or suppress fundamental aspects of physiology, inappropriately impose gendered attitudes on processes more accurately represented by nongendered terms, and negatively influence representations of women, their physiological processes, and their medical needs.	The rhetorical strategy of intensification contests and dislodges unnoticed and untheorized presuppositions in academic arguments by redefining taken-for-granted uses of language.	Intensification, medical anthropology,
Moore	2010	Is the healthy body gendered? Towards a feminist critique of the new paradigm of health	Article	Body & Society 16	ArticleFirst	Critique	The gendered nature of what some refer to as the 'new morality of health', and in particular its urging of feminine attributes, has largely been neglected	Examination of the 'new paradigm' of health and its relationship to femininity	the body, feminization, gender, new paradigm of health
Shahvisi	2019	Medicine is Patriarchal, But Alternative Medicine is Not the Answer	Article	Journal of Bioethical Inquiry	SpringerLink	Narrative	Women who choose alternative therapies are liable to experience inadequate healthcare especially given that the neglect of women's needs within scientific medicine seems to contribute to preferences for alternative medicine	Show that the appeal of alternative medicine to women relates to the neglect of women's health needs within scientific medicine and alternative medicine is severely limited in its therapeutic effects.	Alternative medicine, Women's health, Autonomy, Informed consent, Feminism
Hyde, Nee, Howlett, Drennan & Butler	2010	Menopause Narratives: The Interplay of Women's Embodied Experiences with Biomedical Discourse	Article	Qualitative Health Research 20	ArticleFirst	Qualitative interviews	The cultural authority of biomedicine shapes participants' experiences of the body and how they constituted their health identity	Show the impact of biomedicine in shaping participants' perceptions of their status as menopausal.	embodiment/bodily experiences, ethnography, interviews, medicalization, medicine, women's health
Malterud, Candib & Code	2004	Responsible and responsive knowing in medical diagnosis: the medical gaze revisited	Article	Nordic Journal of Women's Studies 12	ArticleFirst	Qualitative interviews	The medical gaze has been privileged over the voice of the patient as the source of medical knowledge, in western societies.	Create an awareness of the inherent uncertainty of medical knowledge, raise questions about those to whom the knower is accountable, acknowledge the patient's experiences, and attend to the potentially oppressive effects of expert knowing	Medical gaze, diagnosis, medical knowledge, responsible and responsive knowing, accountability, expert knowing

Lian & Robson	2019	Socially constructed and structurally conditioned conflicts in territories of medical uncertainty	Article	Social Theory & Health	SpringerLink	Qualitative analysis of experimental texts	Both experiences and unfulfilled expectations of patients with medically unexplained physical symptoms are influenced by structural factors transpiring from the modern Western biomedical paradigm, and from cultural norms and values of its surrounding society.	Explore the interactional dynamics of clinical encounters fused with medical uncertainty.	Medical uncertainty, Medically unexplained illness, Patient experiences, Clinical consultations—interaction, Non-epileptic seizures, Chronic fatigue/myalgic encephalomyelitis
Malterud, Guassora, Graungaard & Reventlow	2015	Understanding medical symptoms: a conceptual review and analysis	Article	Theoretical Medicine and Bioethics	SpringerLink	Review	A symptom can only be understood by attention to the social context in which the symptom emerges and the dialogue through which it is negotiated, which is often lacking.	Present a conceptual review and analysis of symptom understanding	Symptom assessment, Social values, Communication, Mind–body, Perception, Comprehension
Werner & Malterud	2005	The pain isn't as disabling as it used to be: How can the patient experience empowerment instead of vulnerability in the consultation	Article	Scandinavian Journal of Public Health	ArticleFirst	Review of previous qualitative interviews	Doctors should challenge stereotyped macro-structures of women's "unexplained" pain as hysteria by admitting the shortcomings of medical knowledge. The blame is then put on the medical discipline instead of the individual patient who presents bodily symptoms or reveals help-seeking behaviour that does not fit with biomedical expectations of what illness is and how it should be performed.	Explores how doctors can help patients transform vulnerability into strength, instead of increasing a feeling of disempowerment	Chronic pain, doctor–patient relationship, gender, medically unexplained disorders, qualitative interviews, recognition 'recovery competence', rehabilitation, (women) patients' perspectives
Sebring	2021	Towards a sociological understanding of medical gaslighting in western healthcare	Article	Sociology of Health & Wellness	Wiley Online Library	Narrative	'medical gaslighting' and accompanying accounts of self-identified women experiencing invalidation, dismissal and inadequate care and that medical gaslighting is not simply an interpersonal exchange, but the result of deeply embedded and largely unchallenged ideologies underpinning health-care services.	illuminate the ideological structures of western medicine that allow for medical gaslighting to be commonplace in the lives of women, transgender, intersex, queer and racialized individuals seeking health care	epistemic injustice, institutional gaslighting, intersectionality, medical gaslighting
Migala	2022	Hot air convos: Feeling brushed off during a medical appointment hurts your patient-doctor relationship	Article	Women's Health	Gale General Onefile	Narrative	medical gaslighting. "The term refers to when a health care professional dismisses, invalidates, or belittles a patient's concerns or symptoms.	Offer steps to patients to identify medical gaslighting	medical gaslighting, proactive, patient-doctor relationship

Appendix B – Interview Guide

The diagnosis

- When was endometriosis diagnosed?
- How long did the diagnosis take?
- How long have you suspected you might have endometriosis?
- What were your symptoms?
- How many doctors did you go to? Were they male or female?
- Do you think gender differences played a role in the diagnosis?
- Did you have self-doubt after seeing the doctor?
- Have you questioned your own perceptions?

Feelings

- How did you feel when you first discussed your symptoms?
- Did you feel taken seriously by your doctors?
- Do you feel that your pain is invisible to others?
- Did you feel like you had to convince the doctors?
- How did the doctor react to your symptoms?
- What happened after you left the doctor's office?
- How did you feel when you back home?
- Did you have emotional support from someone during the diagnosis?
- What do you wish would have been different?

Ethics and Privacy Checklist

CHECKLIST ETHICAL AND PRIVACY ASPECTS OF RESEARCH

INSTRUCTION

This checklist should be completed for every research study that is conducted at the Department of Public Administration and Sociology (DPAS). This checklist should be completed *before* commencing with data collection or approaching participants. Students can complete this checklist with help of their supervisor.

This checklist is a mandatory part of the empirical master's thesis and has to be uploaded along with the research proposal.

The guideline for ethical aspects of research of the Dutch Sociological Association (NSV) can be found on their website (http://www.nsv-sociologie.nl/?page_id=17). If you have doubts about ethical or privacy aspects of your research study, discuss and resolve the matter with your EUR supervisor. If needed and if advised to do so by your supervisor, you can also consult Dr. Jennifer A. Holland, coordinator of the Sociology Master's Thesis program.

PART I: GENERAL INFORMATION

Project title: Gendered Knowledge in the Medical World and its Implications for Women with Endometriosis

Name, email of student: Victoria Unverzagt, 493630vu@eur.nl

Name, email of supervisor: Willem Schinkel, schinkel@essb.eur.nl

Start date and duration: 20/03/2022 – 19/07/2022

Is the research study conducted within DPAS YES

If 'NO': at or for what institute or organization will the study be conducted?
(e.g. internship organization)

PART II: HUMAN SUBJECTS

1. Does your research involve human participants. YES

If 'NO': skip to part V.

If 'YES': does the study involve medical or physical research? NO

Research that falls under the Medical Research Involving Human Subjects Act ([WMO](#)) must first be submitted to [an accredited medical research ethics committee](#) or the Central Committee on Research Involving Human Subjects ([CCMO](#)).

2. Does your research involve field observations without manipulations that will not involve identification of participants. NO

If 'YES': skip to part IV.

3. Research involving completely anonymous data files (secondary data that has been anonymized by someone else). NO

If 'YES': skip to part IV.

PART III: PARTICIPANTS

1. Will information about the nature of the study and about what participants can expect during the study be withheld from them? NO
2. Will any of the participants not be asked for verbal or written ‘informed consent,’ whereby they agree to participate in the study? NO
3. Will information about the possibility to discontinue the participation at any time be withheld from participants? NO
4. Will the study involve actively deceiving the participants? NO
Note: almost all research studies involve some kind of deception of participants. Try to think about what types of deception are ethical or non-ethical (e.g. purpose of the study is not told, coercion is exerted on participants, giving participants the feeling that they harm other people by making certain decisions, etc.).

Does the study involve the risk of causing psychological stress or negative emotions beyond those normally encountered by participants? YES

Will information be collected about special categories of data, as defined by the GDPR (e.g. racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data for the purpose of uniquely identifying a person, data concerning mental or physical health, data concerning a person’s sex life or sexual orientation)? No

Will the study involve the participation of minors (<18 years old) or other groups that cannot give consent? NO

Is the health and/or safety of participants at risk during the study? NO

Can participants be identified by the study results or can the confidentiality of the participants’ identity not be ensured? NO

Are there any other possible ethical issues with regard to this study? NO

If you have answered ‘YES’ to any of the previous questions, please indicate below why this issue is unavoidable in this study.

The interview will be about a possible sensitive topic of their endometriosis diagnosis and possible experiences with gender bias. This could cause negative emotions to arise when talking about it.

What safeguards are taken to relieve possible adverse consequences of these issues (e.g., informing participants about the study afterwards, extra safety regulations, etc.).

There will be verbal informed consent. Participants are not forced to answer any questions and are free to leave the interview at any time. Their identities will remain anonymous in the report.

Are there any unintended circumstances in the study that can cause harm or have negative (emotional) consequences to the participants? Indicate what possible circumstances this could be.

As going through medical diagnoses can be an emotional process, recalling this experience can bring forward these emotions. In this case, participants are free to take time to process these emotions or leave the interview if they do not feel comfortable.

Please attach your informed consent form in Appendix I, if applicable.

Continue to part IV.

PART IV: SAMPLE

Where will you collect or obtain your data?

I will collect my data during interviews over Microsoft teams as well as the participants public social media pages.

Note: indicate for separate data sources.

What is the (anticipated) size of your sample?

5 people

Note: indicate for separate data sources.

What is the size of the population from which you will sample?

40,000.

Note: indicate for separate data sources.

Continue to part V.

Part V: Data storage and backup

Where and when will you store your data in the short term, after acquisition?

Private Google Drive folder. All data will be deleted when the thesis trajectory is over at the end of June 2022.

Note: indicate for separate data sources, for instance for paper-and pencil test data, and for digital data files.

Who is responsible for the immediate day-to-day management, storage and backup of the data arising from your research?

Myself only.

How (frequently) will you back-up your research data for short-term data security?

Once a week.

In case of collecting personal data how will you anonymize the data?

Participants will be pseudo names in the report that are allocated randomly.

Note: It is advisable to keep directly identifying personal details separated from the rest of the data. Personal details are then replaced by a key/ code. Only the code is part of the database with data and the list of respondents/research subjects is kept separate.

PART VI: SIGNATURE

Please note that it is your responsibility to follow the ethical guidelines in the conduct of your study. This includes providing information to participants about the study and ensuring confidentiality in storage and use of personal data. Treat participants respectfully, be on time at appointments, call participants when they have signed up for your study and fulfil promises made to participants.

Furthermore, it is your responsibility that data are authentic, of high quality and properly stored. The principle is always that the supervisor (or strictly speaking the Erasmus University Rotterdam) remains owner of the data, and that the student should therefore hand over all data to the supervisor.

Hereby I declare that the study will be conducted in accordance with the ethical guidelines of the Department of Public Administration and Sociology at Erasmus University Rotterdam. I have answered the questions truthfully.

Name student: Victoria Unverzagt

Name (EUR) supervisor: Willem Schinkel

Date: 16/03/2022

Date: 20/03/2022

APPENDIX I: Informed Consent Form (if applicable)

The following research is conducted by the student and data controller representative Victoria Unverzagt, contactable under 493630vu@eur.nl. The researcher is a Sociology student at Erasmus University Rotterdam, which is the data controller. This research is being conducted for the Master thesis. For further information about data protection, the contact detail of the EUR data protection office is privact@eur.nl.

The legitimate interest of the researcher is to investigate women's experience with receiving an endometriosis diagnosis. Participants are encouraged to inform the researcher about the process they went through and additional thoughts they have upon this subject. The legal basis for processing the data is given by the respondent's verbal consent at the start of the interview. Only the student will have access to the data that will be stored on a private google drive folder. Once the research is over the data will be permanently deleted at the end of June 2022. The subject will remain anonymous in the thesis report.

The research subject has rights to access their data upon request to the researcher. The data can be deleted upon request from the subject. The subject may withdraw consent at any time during the research. The subject may lodge a complaint with a third-party supervisory authority.

All information provided to the subject is transparent, concise, presented in a clear and understandable manner and is easily accessible.