**Master's Thesis in Media and Communication Studies**

# Communicating a Silent Disease:

Exploring Health Communication Through Lived Experiences of Endometriosis

May 2026

**Caroline Nieder-Müller**

MSc in Media and Communication Studies

Supervisor: Deniz N. Duru

Examiner: Helena Sandberg

Word Count: 20874

## Abstract

Endometriosis, a chronic inflammatory disease affecting approximately one in ten individuals born with a uterus, remains widely unknown despite its high prevalence. This thesis conceptualizes endometriosis as a "silent disease" characterized by both physical and social invisibility. Drawing on a social constructivist perspective and Harding's (2008) feminist standpoint theory, the study examines how media and health communication shape the visibility, recognition, and understanding of endometriosis, while positioning the lived experiences of those affected as a central source of knowledge.

The thesis is based on four qualitative focus group discussions with ten participants affected by or suspecting endometriosis. The empirical material was analyzed using Kuckartz's (2014) methodological framework for qualitative text analysis with a particular emphasis on an inductive approach inspired by the logic of Grounded Theory.

The findings suggest that individuals with endometriosis must navigate fragmented landscapes of information and support shaped by insufficient institutional health communication. Formal sources were frequently perceived as limited, outdated, or overly generalized, leading participants to rely heavily on participatory communication, particularly through social media. At the same time, participants described repeated experiences of dismissal within healthcare systems and everyday social interactions, contributing to feelings of self-doubt and internalized stigma. The analysis conceptualizes these dynamics as the *Vicious Circle of Silent Suffering*, in which attempts to make the condition visible are frequently met with disbelief or stigmatization, thereby reinforcing further invisibility.

To address this invisibility, participants emphasized that effective communication surrounding endometriosis requires both participatory, bottom-up communication and institutional, top-down initiatives. While participatory communication can provide experiential knowledge and emotional support, institutional communication is necessary to achieve broader public awareness, legitimacy, and structural support. The thesis further develops the concept of the *Triple Burden*, arguing that insufficient health communication forces affected individuals to become (1) self-educators, (2) self-advocates, and (3) participatory communicators. Overall, the findings suggest that health communication surrounding silent diseases is most effective when bottom-up and top-down approaches are integrated and grounded in lived experience.

Keywords: *Silent Diseases, Endometriosis, Health Communication, Lived Experiences, Standpoint Theory, Women's Health, Stigma*

## Acknowledgements

First and foremost, I would like to thank everyone who shared their invisible struggles with me. Without your vulnerability and your trust in me, this thesis would not have been possible.
Thank you for telling your stories!

I am also deeply grateful to everyone who has supported me along the way. Without you, I probably would have given up about 100 times.

Thank you to my supervisor, Deniz, for her thoughtful guidance and valuable feedback throughout this journey. Thank you for trusting my process and for meeting me where I was.

I would also like to thank my classmates and friends – or simply "The Queens of the Library Shelf" – who brainstormed ideas with me, had my back during discouraging moments, and always found something to laugh about. I am glad we went through this together.

Thank you to my parents. Schon zum zweiten Mal durfte ich meine Koffer packen, ins Ausland ziehen und dabei so viele Erfahrungen sammeln. Danke, dass ihr mir etwas ermöglicht habt, das euch so nie möglich war.
And thank you to my entire family (and second family) for always checking in and supporting me from afar.

And finally, thank you, Cedric, for always catching me when I am about to fall, for making me smile every day, for reminding me to take a break, and for exploring the wonderful world outside of libraries with me.

This thesis is for my grandma, who has lived with endometriosis her entire life and never received the care she deserved.
Liebe Oma, diese Arbeit ist für dich – es ist nicht fair, mit einer Krankheit leben zu müssen, die viel zu lange unbeachtet geblieben ist. Ich hoffe, meine Arbeit kann das ein klitzekleines bisschen wiedergutmachen.

# Table of Contents

# 1 Introduction

Approximately one in ten menstruating individuals lives with endometriosis[1]. Yet chances are you just wondered, "Endo-what?" – a common reaction. Despite its high prevalence, the condition remains widely unknown, with significant consequences for those affected.

Often misunderstood as being solely a gynecological condition, endometriosis is a chronic inflammatory systemic disease, mostly affecting people born with a uterus[2]. Tissue similar to the uterine lining grows outside of the uterus and creates lesions. The condition is often described as the 'chameleon of gynecology' (Harder et al., 2024) because it presents with a wide range of symptoms. These include, but are not limited to, severe chronic pelvic pain, irregular bleeding, painful periods, organ dysfunction, fatigue, brain fog, and painful sex. In more severe cases, endometriosis can lead to infertility (Kadhim and Abbas, 2019, p. 458). Beyond its physical manifestations, the presence of pain may cause secondary mental health issues, like anxiety and depression. Importantly, the pain experienced by those affected does not directly correlate with the severity of endometriosis lesions (Brezinka, 2021, p. 136). It is also possible to have endometriosis without experiencing any of the symptoms at all. The symptoms described all have one thing in common: they are invisible on the outside.

Invisible diseases are conditions, often chronic, "that can't be seen by the naked eye" (Salamon, 2023). Endometriosis can be conceptualized as an invisible disease that manifests on two interrelated levels. First, the condition is physically invisible: those affected often appear healthy, while their symptoms remain largely imperceptible to others. Second, and particularly relevant to this thesis, it is socially invisible: despite its high prevalence and significant individual and societal costs, endometriosis remains insufficiently recognized and receives limited public awareness. This dual invisibility contributes to the construction of endometriosis as a *"silent disease"*. While the term *"silent disease"* in medical literature commonly refers to conditions that develop without obvious symptoms (Fuster and Moreno, 2005; Mafi Golchin et

[1] 10% is a reoccurring number in literature. Because of insufficient research, there is uncertainty regarding the true prevalence of the disease (Ghiasi, Kulkarni and Missmer, 2020). Some experts estimate up to 25% (*Educate – Endo What?*, no date).

[2] Throughout this thesis, gender-inclusive language is used where possible to acknowledge that endometriosis can affect trans, intersex, and non-binary individuals. The term "women" is retained in established contexts (e.g., "women's health") and in historical or cited sources and refers primarily to individuals assigned female at birth. Importantly, endometriosis has, in rare cases, also been documented in people without a uterus or without menstruation (Jabr and Mani, 2014; Rei, Williams and Feloney, 2018).

al., 2016), this thesis conceptualizes silence as a condition in which suffering remains physically difficult to perceive and socially insufficiently recognized, communicated, and legitimized.

The consequences of this silence are extensive. Individuals may endure symptoms without recognition, while those who seek medical care often face years of diagnostic delay and limited access to appropriate care. On average, those affected wait between seven and ten years to receive a diagnosis (Shah et al., 2010; Shadbolt, Parker and Orthia, 2013; Nnoaham et al., 2019; Lamceva, Uljanovs and Strumfa, 2023), leaving them in the dark about their condition for years. As a result, endometriosis significantly impairs the quality of life of individuals affected (Nnoaham et al., 2019; Missmer et al., 2021), impacting professional achievements, relationships, and overall physical and psychological well-being (Simoens et al., 2012, p. 1297; Missmer et al., 2022, p. 1). In some cases, the condition shapes major life decisions and constrains the pursuit of personal goals (Missmer et al., 2022). Early diagnosis is crucial, as it can significantly reduce the long-term physical, psychological, and social impact of the disease (Ballard, Lowton and Wright, 2006). An early diagnosis enables earlier treatment, which may reduce long-term complications such as pain and infertility (Shah et al., 2010, p. 650). Beyond the individual level, the disease also imposes a substantial societal burden through increased healthcare costs and productivity losses. Total costs are comparable to those of other chronic conditions, such as diabetes, asthma, and rheumatoid arthritis (Simoens et al., 2012, p. 1292; Hudson, 2022, p. 21).

Although endometriosis is comparable to these other, often similarly invisible, chronic diseases, it remains significantly less understood, researched, and publicly acknowledged. Indeed, the condition "remain[s] poorly elucidated in current scientific works and little progress has been made toward deciphering [it]" (Guidone, 2020, p. 270). Despite being described as the second most common gynecological disease (Mettler and Schmutzler, 2007, p. 300) and affecting individuals globally across social and demographic boundaries (Guidone, 2020, p. 274), it is insufficiently researched medically, and many of its aspects continue to raise questions (Lamceva, Uljanovs and Strumfa, 2023, p. 2). Adding to the silence, endometriosis has consistently been overlooked in government policy and research funding worldwide (Seear, 2014, p. 8; Hudson, 2022, p. 21), and professional and public awareness remain low (Zondervan, Becker and Missmer, 2020, p. 1244).

This lack of social visibility is closely tied to persistent gaps in both professional and public knowledge about endometriosis. People with endometriosis perceive healthcare providers' knowledge as limited and outdated (Sbaffi and King, 2020, p. 385), which can lead to

misinterpretation of symptoms and delayed diagnoses. Furthermore, inadequate knowledge can lead to a lack of understanding and empathy towards the patients, which negatively influences the care and well-being of individuals with endometriosis (Senyel, Boyd and Graham, 2025, p. 2). Importantly, the psychological burden associated with endometriosis cannot be understood solely as a consequence of the disease itself, but is also shaped by negative experiences within the healthcare system, including disbelief and dismissal (Culley et al., 2013, p. 636; Guidone, 2020, p. 273).

At the same time, public awareness of endometriosis remains strikingly low. Studies show that a substantial proportion of the population has little to no knowledge of the condition (Shah et al., 2010, p. 648), and even among young people, many have never heard of it (Shadbolt, Parker and Orthia, 2013, p. 152). Men know significantly less about endometriosis than women (Shah et al., 2010), and three out of four participants in Shadbolt et al.'s (2013) study highlighted that men should also be educated about the condition, since they are potential partners, friends, or parents to someone with the disease. In this sense, invisibility is not merely a characteristic of the disease, but is actively reproduced through gaps in knowledge and recognition.

It is essential to increase awareness and understanding of endometriosis within the healthcare system and society. Against this backdrop, health communication plays a crucial role. By providing information and education, and thereby influencing health-related attitudes and behaviors (Lewis and Lewis, 2015, p. 5), it is an important factor in reducing the severity and long-term impact of many health issues (Wright, Sparks and O'Hair, 2012, p. 4).

**Research Aims and Research Questions**

This thesis is situated within media and communication studies, specifically in the field of health communication, with a particular focus on gendered health and silent diseases. Drawing on Harding (2008), it adopts a feminist standpoint perspective, positioning the lived experiences of those affected as a central source of knowledge. The study is designed as a qualitative case study, examining endometriosis as a paradigmatic example of a silent disease. It aims to explore the role of media and health communication in shaping the visibility, recognition, and understanding of endometriosis as a silent disease. In doing so, the study seeks to identify ways to communicate silent diseases effectively to enhance public awareness and promote earlier recognition among those at risk, thereby contributing to the field of health communication.

Central to this study are the lived experiences of individuals with endometriosis, explored through focus group discussions and treated as a valuable epistemic resource. By foregrounding

these perspectives, this thesis also responds to a notable gap in existing research. As Seear (2014) highlights, "only a handful of studies have been conducted which give voice to women" (p. 6), and "the thoughts and feelings of women with endometriosis about their future lives do not feature in the previous literature" (Denny, 2004, p. 646). The present study contributes to the growing body of work that centers patient perspectives within health communication research.

The following three research questions will guide this thesis:

1. **How do individuals with (or with suspected) endometriosis navigate and evaluate sources for information and support in their endometriosis journey?**
2. **How do those individuals perceive and reflect on the role of media and communication in shaping awareness, recognition, and understanding of the condition?**
3. **What does the case of endometriosis reveal about the role of health communication in shaping the visibility of "silent diseases"?**

The structure of this thesis is as follows. The final chapter of this introduction contextualizes endometriosis and offers important background. The second chapter combines the theoretical framework with current literature to examine the social construction of the silence surrounding endometriosis and to introduce key perspectives within health communication. The third chapter outlines the methodological considerations and research method applied in this study. It explains the suitability of qualitative focus group discussions for the research aims and reflects on the research process, including ethical considerations and limitations. The fourth chapter presents the analysis, which is divided into three sections corresponding to the research questions. Finally, the conclusion summarizes the main findings, acknowledges limitations, and highlights the thesis's central contributions.

## Contextualizing Endometriosis

This thesis provides what may appear to be extensive contextual information on endometriosis. This is intentional. In light of persistent misinformation and limited public awareness, a comprehensive understanding of the condition is essential for grasping the scale of an issue that remains systematically silenced.

### *The Diagnosis*

The diagnosis of endometriosis is difficult. This is due to its diverse symptomatology and because its true pathogenesis remains poorly understood (Lamceva, Uljanovs and Strumfa,

2023, p. 1). A consultation and physical examination, including transvaginal ultrasound or magnetic resonance imaging (MRI), performed by a trained healthcare provider, may lead to a suspected diagnosis. This approach may be sufficient to start treatment. However, surgical visualization, ideally laparoscopy, remains the standard for confirming the diagnosis (Zondervan, Becker and Missmer, 2020, p. 1251). As mentioned above, it often takes years to receive a diagnosis. Research has called for a shift toward faster, less invasive diagnostic methods rather than relying on surgical diagnosis, to reduce diagnostic delay (Taylor, Kotlyar and Flores, 2021, p. 840).

***No Cure and Limited Treatment Options***

To date, there is no cure for endometriosis. Contemporary treatment options are limited and focus solely on symptom relief (Hudson, 2022, p. 23).

The medical treatment includes pain medication and hormonal medicines, for example, the contraceptive pill. Research has remarked that both of these treatment options are "flawed" and can be "entirely ineffective for the reduction of patient suffering" (Ellis, Munro and Clarke, 2022, p. 1). Surgical treatment in the form of a minimally invasive laparoscopic excision aims to remove all endometriosis lesions, adhesions, and scar tissue (World Health Organization, 2025). However, the success of this intervention may depend on the surgeon's skills (Zondervan, Becker and Missmer, 2020, p. 1253). In addition, there remains a risk of lesions recurring after successful removal (Seear, 2014, p. 5).

In some cases, a hysterectomy (surgical removal of the uterus) is considered for individuals who do not respond to other therapies and do not intend to have children. However, it is important that a hysterectomy is not a cure for endometriosis. It causes significant side effects, and symptoms can persist for some patients (Jones, 2015, p. 1106; World Health Organization, 2025). Importantly, pregnancy is not a cure for endometriosis either. It has long been suggested as a 'treatment' for endometriosis, a notion rooted in outdated and misogynistic ideas that menstrual pain was a punishment for infertility, but this claim is entirely unsupported by clinical evidence and is not recognized in modern medical practice (Guidone, 2020, p. 271).

The (limited) range of treatment options is shaped by factors such as severity, individual preferences, potential side effects, long-term safety, costs, and availability (World Health Organization, 2025). This short chapter highlights that individuals affected by endometriosis not only face a lack of treatment options but also a degree of uncertainty, where access to effective care can depend heavily on encountering knowledgeable healthcare professionals at

the right time. This situation is closely linked to the broader lack of research funding and scientific attention devoted to the condition. An absence that both reflects and reinforces the silence surrounding endometriosis. As Harder et al. (2024) emphasize, "increased funding for endometriosis research can lead to a better understanding of the condition, bridging knowledge gaps, faster diagnosis, more treatment options, cost reduction, improved pain management, and a much-needed focus on female experiences of illness and quality of life" (p. 896).

***Endometriosis in Sweden***

This thesis takes Sweden as its empirical context. Although Sweden's National Board of Health and Welfare published national guidelines for the management of endometriosis in 2018 (Socialstyrelsen, 2018), and the country recently opened its first specialized endometriosis clinic in Stockholm (SVT Nyheter, 2024), the time to diagnosis remains five to seven years. This estimate is highlighted in a digital exhibition by Stockholm's Museum of Women's History, raising awareness about endometriosis (Kvinnohistoriska Museum, 2024).

Qualitative research based in Sweden further illustrates how endometriosis manifests as a silent disease in practice. Based on interviews with individuals diagnosed with endometriosis, Hallström (2024) shows that individuals often have to "struggle for diagnosis" to have their condition recognized. Similarly, Swedish people with endometriosis have used blogs to mediate their experiences with the healthcare system as "protracted struggle" (Grundström et al., 2020). These studies suggest that individuals in Sweden experience patterns comparable to those reported internationally, pointing to a broader, systemic silence surrounding endometriosis. This is particularly notable given that Sweden's healthcare system is "highly regarded worldwide" (Cancarevic, Plichtová and Malik, 2021, p. 67). The persistence of diagnostic delays and patient struggles, therefore, indicates that endometriosis remains silenced even within well-resourced systems.

The Swedish context was primarily chosen to provide a shared frame of reference for participants and to support coherent data collection, ensuring familiarity with a common healthcare system. While the focus group discussions centered on the Swedish context, they were enriched by participants' experiences from various national backgrounds (see *Chapter 3*). At the same time, the findings of this study align closely with international research, suggesting that the silencing of endometriosis is not confined to a specific national context, but may instead be understood as a broader, transnational phenomenon.

# 2 Theoretical Framework and Literature Review

This chapter combines theoretical perspectives with recent empirical literature to establish the foundation for the analysis and position this thesis within existing academic discussions on gendered health, silence, stigma, and health communication. The first section examines how silence surrounding women's health issues is socially constructed and maintained through dominant forms of knowledge production, gendered medical discourse, and social stigmatization. The second section shifts toward health communication and explores how communication strategies may respond to the invisibility of silent diseases. In particular, the section discusses the relationship between media and health communication, as well as the differences between top-down and bottom-up communication approaches, which later become relevant in the analysis of endometriosis communication. Since silence itself presents a communicative challenge, these perspectives provide the tools necessary to analyze how endometriosis is communicated, negotiated, and made visible.

### A Theoretical Approach to Women's Health

To understand why endometriosis remains underrecognized, this thesis first explores how knowledge is produced. Drawing on Sandra Harding's (2008) critique of Western, male-centered knowledge production, this thesis adopts a feminist standpoint approach to challenge dominant scientific perspectives and foreground experiences long marginalized within scientific discourse. A social constructivist perspective further supports the analysis by emphasizing how understandings of health and disease are socially negotiated rather than purely objective or fixed. Within this framework, Deborah Lupton's (2012) work on feminist perspectives in medicine provides an important foundation for understanding how the female body has been understood and regulated within medicine. Her discussions of Michel Foucault's theories of bodies, power, and medical authority further contribute to the analysis by illustrating how medical institutions regulate and define legitimate knowledge about the body. At the same time, the case of endometriosis complicates a purely Foucauldian understanding of medical power, as medical encounters may not only function as sites of control but also as spaces of recognition and validation for those affected. To contextualize these dynamics, the chapter further engages literature on the historical marginalization of women's health concerns, including discussions surrounding hysteria and the dismissal of women's pain. Finally, Erving Goffman's (1986) stigma theory helps explain how chronic illness may produce social stigmatization and shape the experiences of those affected. Together, these perspectives provide

the theoretical basis for understanding how silent diseases such as endometriosis are socially produced and maintained.

### *Knowledge Production and Harding's Standpoint Theory*

Endometriosis is described as being identified microscopically by Karl von Rokitansky in 1860 (Batt, 2011), more than 160 years ago. Nevertheless, the disease remains largely unknown to this day. This raises questions about how certain conditions become visible within medical and public agendas while others remain neglected.

Female perspectives have long been disregarded in scientific research. In her book, which takes a critical feminist perspective on modern sciences, Harding (2008) argues for challenging the existing politics of the sciences by adopting a feminist standpoint approach. She states that the structure of society shapes the production of scientific knowledge, as social hierarchies have epistemological consequences: "knowledge and power are internally linked" (Harding, 2008, p. 117). What people do depends on their position in social structures, and both enables and limits what they know (Harding, 2008, p. 117). She argues that dominant perspectives often align "distressingly" closely with men's conceptions of social and scientific issues (Harding, 2008, p. 116). Because these perspectives resonate with the interests of men in positions of power, they have been granted authority and become institutionalized (Harding, 2008, p. 116).

Applied to the case of endometriosis, this raises questions such as: "Whose suffering is recognized?", "Which conditions are legitimized as diseases?", "What is worth researching?", and "What is worth informing the public about?". Such considerations indicate that the sciences play an important role in maintaining power hierarchies, whether intentionally or not (Harding, 2008, p. 120). Transformation is challenging and slow, as even critical scholars operate within social structures and institutions shaped by dominant understandings of society (Harding, 2008, p. 119). This dynamic creates a self-reinforcing cycle in which established perspectives continue to shape what is known and valued. Standpoint theory seeks to interrupt this cycle by producing knowledge that is *for* women, not just about them (Harding, 2008, p. 114; emphasis in original). The idea is to "insist on looking at the ways in which women's lives are enabled and constrained by the assumptions and practices of dominant institutions" (Harding, 2008, p. 117). Rather than completely breaking free from the dominant understanding, it calls for a degree of critical distance achieved through collective inquiry and struggle, enabling marginalized groups to "come to voice" and be empowered (Harding, 2008, pp. 120-121). Whereby the sciences systematically fail to account for women as agents and subjects and to include their experiences (Hudson, 2022, p. 22), the standpoint approach centers women as

agents and subjects of science and history and, thereby, intends to transform the existing politics of the sciences into ones that recognize women as just as fully human as men (Harding, 2008, p. 122-123).

Feminist standpoint research is filling a gap by providing women with "information about their bodies, their environments, and how social institutions work[…] that the existing natural and social sciences did not think worth pursuing" (Harding, 2008, p. 115). This is where this thesis aims to make a contribution. By researching health communication starting "from women's lives", this thesis positions itself as a feminist standpoint study within "sciences from below" (Harding, 2008, p. 115). In the context of this thesis, adopting a standpoint approach began with choosing a topic directly from the lived reality of people assigned female at birth and aiming to make something apparently invisible visible. It further "gives a voice" to a marginalized group (Harding, 2008, p. 124), in this case, people born with a uterus, and takes seriously the experiential knowledge of those affected by endometriosis.

### *Social Constructivist Perspective on Medicine, Health, and Disease*

This thesis is grounded in social constructivist principles. Social constructivism questions the existence of "truth". Rather, it presumes that everything is inevitably the product of social relations and power dynamics and is never neutral, as it always serves someone's interest (Lupton, 2012, pp. 8–9). This includes the production of knowledge, as argued in the chapter before.

Using this lens, medicine, health, and disease can also be seen as social products and should, therefore, be explored through social analysis (Lupton, 2012, p. 9). The way scientific knowledge is used to privilege the position of powerful groups over others also applies to medical knowledge (Lupton, 2012, p. 9). Thus, some groups receive more attention in medical research and practice than others. It becomes clear that "medical beliefs are never just the products of objective science but are equally likely to be reflections of shifting whims of social norms" (Nezhat, Nezhat and Nezhat, 2012, p. 56).

### *Body Politics and Foucault*

*"Human bodies have been seen as clay, moulded by political and economic constraints" (Sassatelli, 2012, p. 358)*

As part of medicine, health, and disease, "the human body can no longer be considered a given reality, but as the product of certain kinds of knowledge and discourses which are subject to

change“ (Lupton, 2012, p. 21). The body can, thus, be described as a “battlefield” formed by conflicts between groups with different values and interests (Sassatelli, 2012, p. 359).

Drawing on the work of philosopher Michel Foucault, Lupton (2012) emphasizes that the body is deeply embedded within political structures, serving as a primary site for control, surveillance, and regulation. Foucault’s work has been crucial in recognizing how power relations are enacted through and upon the body (Sassatelli, 2012, p. 352). According to Lupton (2012), Foucault argued that diseases have historically shifted from being understood as individual concerns to becoming economic and political problems for society (p. 16), constituted not only within the individual but also within the social body (p. 33). As a result, disease and “deviant types” required collective control measures for the sake of the health of the whole population (Lupton, 2012, p. 33). As briefly mentioned in the introduction, endometriosis has likewise been described as a societal burden, particularly for its “substantial” economic impact (Gao et al., 2006, p. 1569). However, only limited collective measures have been implemented to address the condition, while dominant power structures have instead contributed to its continued neglect.

According to Turner (1997), Foucault saw the controlling power over the body “embodied in the day-to-day practices of the medical profession within the clinic” (pp. xi-xii) and the medical system itself. The people in power and their constructed normality were challenged by those who deviated from it, who were seen as a threat and as ones who ought to be controlled. Medicine acts as a major institution of power in labeling bodies as deviant or normal (Lupton, 2012, p. 23). In her discussion of Foucault, Lupton (2012) notes that he regarded the medical encounter as a “supreme example of surveillance” (p. 24), in which patients possess limited knowledge, creating an unequal power dynamic between doctor and patient. In the context of endometriosis, this imbalance can become especially visible when healthcare professionals use their authority and knowledge, or lack thereof, to dismiss or minimize patients’ experiences. At the same time, being listened to, taken seriously, and ultimately receiving a diagnosis can be invaluable for individuals suffering from the diffuse and often misunderstood symptoms associated with endometriosis, thereby pointing to a more positive dimension of the medical encounter than the one emphasized by Foucault.

### *The Female Body: Oppression and Marginalization throughout History*

Understanding endometriosis as a silent disease also requires examining the gendered dimensions of medicine and healthcare. Female health, the female body, and its anatomy have fallen short in medicine for centuries (Lupton, 2012, chap. 6). Historically, the male body has

been treated as the "standard body" in human anatomy. In contrast, the female body has been presented as "a variation on standard humanity" (Criado Perez, 2019, p. 227), the "incomplete version" of the male, characterized as weaker, unstable, and defective (Lupton, 2012, p. 138). These perspectives persist in medical textbooks to this day, "making it impossible to learn female anatomy without first learning male anatomy" (Lupton, 2012, pp. 138–139). Beyond textbooks, such imbalances are also reflected in medical-school curricula (Criado Perez, 2019, p. 229). The widespread bias favoring individuals assigned male at birth negatively affects the health and medical treatment of women and gender minorities across many societies and on multiple levels (Mayat, Rivera and Lane, 2022, p. 27).

It is important to note that within feminist discussions of the body and medicine, a persistent tension exists between validating people assigned female at birth's unique embodied experiences and rejecting the idea of gender differences entirely (Lupton, 2012, pp. 137-138). This tension reflects a delicate balance between calls for equality and the recognition of difference. On the one hand, individuals assigned female at birth have long struggled for equal treatment and for their health concerns to be afforded the same legitimacy and attention as those of individuals assigned male at birth. On the other hand, certain health conditions manifest differently in people assigned female at birth, one famous example being the presentation of stroke symptoms, and other conditions are entirely specific to their reproductive anatomy. This tension becomes particularly relevant in the context of endometriosis and other gender-specific conditions, where the recognition of embodied difference is necessary for adequate diagnosis, treatment, and medical legitimacy.

In her book *Invisible Women: Data Bias in a World Designed for Men*, feminist author Criado Perez (2019) argues that male and female bodies differ down to a cellular level (p. 231). She further explains that these differences have not been sufficiently recognized in medicine because "sex-specific information … is dependent on the availability of sex-specific data, but because women have largely been excluded from medical research this data is severely lacking" (p. 231). Importantly, acknowledging sex differences is not a call for unequal treatment, but for equitable and context-sensitive care. Historically, however, such differences have been interpreted through patriarchal frameworks as evidence of female inferiority and used to justify women's exclusion from public and economic spheres, a practice that has been strongly critiqued in feminist scholarship (Lupton, 2012, p. 138).

Rather than being mutually exclusive, these feminist perspectives highlight the complexity of addressing gender inequality in medicine, particularly in cases where biological differences have historically been either ignored or used to justify discrimination.

Endometriosis exemplifies these broader patterns of omission and gendered construction within medicine. Scholars have linked the persistent challenges in diagnosing, treating, and funding endometriosis to a combination of a lack of adequate research data and the longstanding neglect of women's health issues more broadly (Harder et al., 2024, p. 896).

***Hysteria, Stigma, and the Pathologization of Women's Health***

The silence surrounding endometriosis is closely linked to the historical marginalization and stigmatization of women's bodily experiences. Within patriarchal systems, illnesses commonly affecting people assigned female at birth have been systematically ignored or misattributed as evidence of mental illness or deviant behavior (Guidone, 2020, p. 273; Hudson, 2022, p. 22). As Lupton (2012) notes, "women were seen as being controlled by their uterus and ovaries" (p. 141). This belief is also reflected in the etymology of the term 'hysteria', derived from the Greek word *hysterikos*, meaning 'of the womb' (Guidone, 2020, p. 273). In her work on gynecological narratives of menstruation in the late nineteenth century, Strange (2000) cites a practitioner who advised that "women who frequently displayed nervous or hysterical symptoms in relation to menstruation ought to be incarcerated for their own safety and for the good of society" (p. 616). Such statements illustrate how the bodily experiences of those assigned female at birth were pathologized and framed as threats requiring social control. More recently, Nezhat et al. (2012) have described hysteria as potentially "one of the most colossal mass misdiagnoses in human history" (p. 1). The authors argue that irrefutable evidence suggests that hysteria, long regarded as a psychological disorder, was, in many cases, likely undiagnosed endometriosis (Nezhat, Nezhat and Nezhat, 2012, p. 1).

The misconceptions and discrediting structures have meant that people with a uterus experiencing health issues often face being outcast or stigmatized. Building on earlier discussions of how women's bodies have been constructed within medical discourse, Lupton (2012) describes how women have been positioned as the "Other" (p. 138). This notion aligns with Goffman's (1986) theory of stigma, in which he distinguishes between "normals" and "others" who are "the stigmatized". In *Stigma: Notes on the Management of Spoiled Identity*, Goffman describes how individuals who, in the eyes of society, deviate from the "normal", fall victim to stigmatization. Therefore, stigma is a relational phenomenon: it emerges not from the attribute itself, but from the interaction between an attribute and an audience's perception of it.

Stigma is therefore context-dependent and socially produced rather than inherent to the individual. Expanding on this, Barth (2008), in his discussion of Foucault's *Madness and Civilization: A History of Insanity in the Age of Reason*, captures the idea that the "normal" tend to close their eyes to the "mad", or the "other", to secure the boundaries of their normality (p. 61). In other words, it is easier to categorize and marginalize than to question and adapt one's own normality.

Goffman (1986) distinguishes between felt and enacted stigma. Felt stigma describes the sensation of feeling less than normal, stigmatized within, because an attribute doesn't align with the audience one is facing. Enacted stigma, on the other hand, refers to people with a certain attribute being actively stigmatized, which may lead to overt discrimination. In the case of endometriosis, both forms of stigma become relevant. Importantly, stigmas can be invisible, at least at first sight, or visible. The relationship between stigma and illness reveals that every illness stigmatizes the individual to a lesser or greater extent. However, chronic diseases, such as endometriosis, carry a much heavier burden of stigma. This leads to people putting great effort into hiding their condition. Goffman (1986) identifies acceptance as a central dilemma for stigmatized individuals. Those affected seek acceptance and do not want to be reduced to their stigma, in this context, their chronic disease. However, societal responses often fail to provide this recognition, leaving individuals with feelings of exclusion and deep insecurity.

While, according to Goffman, stigmatization may happen to anyone, the concept is discussed here in the concrete form of individuals assigned female at birth being stigmatized. In the context of endometriosis, those affected often face two branches of societal stigma: menstrual stigma and endometriosis as a gendered, chronic disease stigma.

First, menstrual stigma persists and remains deeply rooted in history. As Lupton (2012) explains, "in the 19th and early 20th centuries menstruation and pregnancy were treated as abnormal – as sicknesses rather than normal bodily functions" (p. 141). The perceived public stigma surrounding menstruation is associated with greater self-stigmatization and a reduced willingness to engage in dialogue with others (Hallström, 2024, p. 8; Eitze and Reinhardt, 2025, p. 1028). This aligns with Goffman's (1986) argument that stigmatized individuals internalize dominant standards of normality and apply them to themselves. Although endometriosis is now medically recognized as a systemic disease, it remains strongly associated with menstruation, particularly because painful periods are among its most recognized symptoms. The stigma and silence surrounding menstruation, and therefore endometriosis, contribute to a normalization of symptoms. As Gender Studies scholar Hallström states in an interview, if one cannot compare

one's own experiences with others, it is impossible to know what a "normal" experience is (Kvinnohistoriska, 2024). This dynamic illustrates how stigma and silence reinforce one another, making it more difficult for those affected to recognize their experiences as abnormal, medically significant, or worthy of open discussion.

The second branch of stigmatization is the stigma of endometriosis itself. Seear (2014) declares endometriosis as a "highly stigmatized condition", since it is "negotiated around the meanings of blood, menstruation, pain, fertility and infertility" (p. 6), linking menstrual stigma and endometriosis. In addition, the lack of sufficient information about endometriosis often leads to misconceptions and, subsequently, to the stigmatization of individuals born with a uterus (Tragantzopoulou, 2024, p. 117).

***The Normalization and Dismissal of Pain***

In a study on endometriosis-related stigma among Latina women, Matías-González et al. (2021) found that participants described endometriosis as "changueria", "a term used to label or describe someone as being an excessive whiner or complainer without an apparent reason" (Sims et al., 2021, p. 5). Describing the same phenomenon, Guidone (2020) uses the label "menstrual moaners" (p. 272). Such perceptions are reinforced by family members, employers, and the broader public, all of whom may fail to recognize the severity of endometriosis-related pain. Healthcare professionals, in particular, often trivialize menstrual pain, creating a significant obstacle for those seeking care (Seear, 2014, p. 9). Women's pain is frequently minimized, invalidated, or dismissed as "imaginary" (Bloski and Pierson, 2008, p. 8), while those who disclose their symptoms are told that they are "just in [their] heads" (Whelan, 2007, p. 973).

In this context, Hallström (2024) coined the term "pedagogy of pain" to describe the common belief that menstrual pain is normal. It "perpetuates variations of the theme that menstruation hurts and that womanhood is inherently painful" (Hallström, 2024, p. 11). Tragantzopoulou (2024) argues, "menstrual pain is unjustly normalized as something women should endure" (p. 117).

These conflicting perceptions are reflected in Krebs & Schoenbauer's (2019) contrapuntal analysis, which identifies two paradoxical discourses: psychological-abnormality and biological-normality. While the former frames endometriosis symptoms as psychological or "in their heads", the latter treats them as normal aspects of womanhood (Krebs and Schoenbauer,

2019, p. 1020). These discourses demonstrate how normalization and psychologization operate simultaneously, producing communicative and medical barriers to recognition and care.

As a result, people born with a uterus may avoid disclosing their symptoms out of fear of appearing irrational, weak, or unable to cope with what they have been taught to perceive as "normal, albeit painful, periods" (Ballard, Lowton and Wright, 2006, p. 1298). This further illustrates how stigma becomes internalized and contributes to the silence surrounding endometriosis.

Together, these perspectives help explain why endometriosis remains both medically underrecognized and socially invisible despite its high prevalence. The historical marginalization of women's health, combined with the stigmatization and normalization of menstrual pain, contributes to a broader silence surrounding the condition. As Hudson (2022) argues, this silence shapes contemporary understandings of endometriosis, which are limited in their ability to represent the lived realities of those affected (p. 24). Her description of endometriosis as a "missed disease" captures how the condition continues to fall between medical, social, and political recognition. Against this backdrop, scholars and advocacy organizations have increasingly called for greater awareness and visibility surrounding endometriosis.

**Health Communication: A Response to Silence**

If silence contributes to the invisibility of endometriosis, health promotion becomes one possible way of challenging that invisibility. Lewis and Lewis (2015) define health promotion as "the process of enabling people to increase control over their health as well as the factors that influence [it]" (p. 7). Health communication, in turn, is fundamental to every aspect of health promotion (Lewis and Lewis, 2015, p. 7). Health communication generally aims to provide people with information, education, and health-related messages to shape their attitudes, beliefs, and behaviors, as well as the factors that influence their behavior choices (Lewis and Lewis, 2015, p. 5). More recently, health communication efforts have taken a more socio-ecological approach, focusing on the multiple levels of influence on people's health (Lewis and Lewis, 2015, pp. 7–8).

In the context of invisible conditions like endometriosis, health communication helps shed light on them, given the lack of public and professional awareness. Furthermore, it can break the silence surrounding the disease, as it can effectively mitigate societal stigmatization associated

with certain medical conditions (Kasturia, 2023, p. 114). Wright and colleagues (2012) argue that the severity of many health issues could potentially be reduced by improving health communication (p. 4). While improved communication is not the solution for all health issues, "it is an important underlying factor" (Wright, Sparks and O'Hair, 2012, p. 5). It has the potential to contribute to the reduction of "incidents of disease and human suffering, … while increasing physical well-being and satisfaction with healthcare among members of society" (Wright, Sparks and O'Hair, 2012, p. 5). Researching health communication on endometriosis is therefore relevant, as it helps to gain a better understanding of the communication practices and ultimately aims to reduce suffering for those affected.

In their book, *Health Communication: A Media and Cultural Studies Approach*, Lewis and Lewis (2015) argue that "media is implicated in all health promotion strategies" (p. 5), which makes it particularly relevant to this thesis. Health communication happens on different levels. Wright et al. (2012) differentiate between interpersonal, organizational, or mass-mediated contexts of health communication. Lewis and Lewis (2015) take a different route, arguing that health communication is gradually evolving from expert-driven, top-down approaches to include more community-focused, participatory, bottom-up approaches (p. 12). This latter framework will guide the analysis of this thesis. Within it, health communication can take various forms. Two illustrative examples, one for a top-down and one for a bottom-up approach, will be presented below.

### *Top-Down Communication: The Effectiveness of Health Campaigns*

Public health campaigns are a typical form of top-down health communication. As a form of strategic communication, public communication campaigns are defined as "purposive attempts to inform or influence behaviors in large audiences within a specified time period using an organized set of communication activities and featuring an array of mediated messages in multiple channels generally to produce noncommercial benefits to individuals and society" (Rice and Atkin, 2013, p. 3). Public health campaigns often follow the logic of social marketing. Lewis and Lewis (2015) explain that by "using models and theories derived from a combination of psychology and commercial marketing, social marketing enable[s] health promoters to develop more targeted and effective media campaigns" (p. 82). The authors go on, "This approach is often described as 'persuasive' communication because it moves beyond traditional health information and education" (pp. 82-83). While public health campaigns are often understood primarily as tools for behavior change, Werder (2020) argues that campaigns targeting behavior are almost always also concerned with shaping awareness and attitudes.

Lewis and Lewis (2015) attribute even more outcomes to social marketing campaigns: “Social marketing campaigns can be effective for: raising awareness, increasing knowledge, prompting people to seek information and services, changing attitudes, beliefs, and intentions to change behavior, and achieving some changes in behavior” (p. 83). Moreover, these campaigns aim to contribute to shifting social norms related to the issue addressed (Pryor et al., 2025, p. 2).

Typically, public health campaigns have been primarily disseminated through the mass media. In recent years, with the rapid development of new media platforms, “campaigns have become increasingly creative and diverse with their channel strategies” (Zhao, 2020, p. 12).

Research on health campaigns consistently demonstrates their potential to shape awareness, knowledge, attitudes, and behaviors among large audiences. In a review, Wakefield et al. (2010) discussed the outcomes of mass media campaigns in the context of various health-risk behaviors, such as tobacco use, as well as cancer screening and prevention. They found that mass media campaigns can produce changes, or prevent negative changes in health-related behaviors across large populations (Wakefield, Loken and Hornik, 2010, p. 1268). These results were confirmed by another review by Anker and colleagues (2016), showing that campaigns had a significant positive effect on behavior change and knowledge. The latter is especially interesting for the case of endometriosis. More recently, Abdo (2023) analyzed the role of awareness campaigns in the context of rare diseases. The author attests to a “vital role” of awareness campaigns and confirms a correlation between awareness campaigns and the prominent level of health awareness among members of society (Abdo, 2023, p. 82).

As demonstrated, numerous studies have confirmed the effectiveness of public health campaigns. Endometriosis research has repeatedly emphasized the potential of public health campaigns to increase general public awareness (e.g., Sims et al., 2021; Tragantzopoulou, 2024). However, endometriosis in relation to public health campaigns has rarely been researched. Only one study by Stanek et al. (2023) examined the endometriosis-related social media health campaign *#1in10*. The campaign was co-created by the Danish Endometriosis Patient Association and women with endometriosis, implementing a blend of expert-driven and participatory approaches, as discussed above (and below) with regard to Lewis and Lewis (2012). Stanek et al.’s (2023) study underscores the campaign’s positive impact at three levels: the individual level for participating patients, the communal level for people with endometriosis, and the broader societal level.

### *Bottom-Up Communication: Participatory Health Communication through Social Media*

As mentioned earlier, Lewis and Lewis (2015) suggest a shift towards participatory health communication, which means working *with* communities, rather than *on* them, when communicating about health and social change (Lewis and Lewis, 2015, pp. 7, 104). This approach follows the idea that audiences are no longer "passive 'receivers' of health communication but rather active participants in meaning-making and 'media-making'" (Lewis and Lewis, 2015, p. 12).

Eleven years ago, Lewis and Lewis (2015) only anticipated the growing role of social media in participatory health communication. They write, "social networking sites (SNS) offer a novel environment for health promotion due to their popularity, interactivity and potential to engage and create communities" (p. 136). Now, only a decade later, social media, with its user-generated content, is a central example of participatory media. It provides the structure for participation by creating "a unique arena, where everyone with internet access can easily find, generate, and share content with the world" (Stanek et al., 2023, p. 2). The platforms are easily accessible and provide a broad public with "straightforward ready information" (Arena et al., 2022, p. 101). That is why in today's digital context, the internet, and social media in particular, have become crucial resources for health communication. The technologies allow people to become active participants in their health journey rather than being passive recipients (Lupton, 2017, pp. 5–6). In the context of endometriosis, this takes on particular significance given the findings of van den Haspel et al. (2022), which reported that in a sample of 100 Australian patients with a confirmed diagnosis of endometriosis, 76% used social media as a health-related self-management tool. This suggests that social media increasingly functions as an alternative source of health information and support in contexts where institutional knowledge and public awareness remain insufficient.

Stanek et al. (2023), the authors of the only study on an endometriosis-related health campaign, demonstrate the power of participatory health communication when they report in their findings: "the [online] community engaged with the campaign and added significantly to the dissemination of its message" (p. 1).

Not only is it possible for anyone to contribute by disseminating health communication efforts, but digital platforms also allow users from diverse backgrounds to generate content. Users share their experiences, educate others, and advocate for health-related topics, such as endometriosis. Very active users may also be considered influencers, or, in this case, "endometriosis

influencers" (Shiplo et al., 2025). Interestingly, Shiplo and colleagues (2025) discovered that most endometriosis-related posts and accounts on Instagram were created by people living with endometriosis themselves, which "underscores the importance of patient voices in the digital space, particularly in communities discussing chronic pain conditions" (p. 697). Furthermore, Vicari (2021) refers to users engaging in this form of participation as "lay experts", creating content at the intersection of "experiential" and "expert" knowledge (p. 127).

Endometriosis, in the context of social media, has increasingly attracted interest from the scientific community in recent years. Melander (2019), for instance, analyzed how endometriosis is narrated on an activist Instagram account shared by five women who post about their experiences living with the disease. Seo et al.'s (2025) study of endometriosis-tagged posts found that people with endometriosis use Instagram to create an online public sphere to raise awareness of the disease, connect with and support others affected, and advocate more broadly for women's health and well-being. Holowka (2022) explored how people with endometriosis expand the simplistic view of the condition by mediating their pain and experiences on social media. Her study also revealed that people with endometriosis often use social media to understand, experiment with, and navigate their symptoms (Holowka, 2022, p. 1), especially since they often receive limited information from healthcare professionals. All of these studies show that people with endometriosis, in response to a lack of alternatives, turn to social media content to find health information, and that social media, in turn, can foster health communication. However, it is essential to note that health content on social media primarily reaches those already engaged with the topic, rather than advocating for broader public awareness (König and Meier zu Biesen, 2025, p. 2).

Research has repeatedly highlighted a downside of social media in health communication. User-generated content bears the risk of containing false or fraudulent information. This is especially harmful when the content is health-related and aims to inform people affected by diseases. However, Shiplo et al. (2025) found that 85% of the endometriosis-related posts they analyzed contained accurate information. In Towne et al.'s (2021) sample of endometriosis-related content, even 94% of educational posts were accurate. It is still noteworthy that, by focusing not only on social media but on online information in general, over 75% of participants in a study by Arena et al. (2022) encountered an average of 2.2 erroneous statements about endometriosis online. This is significant, especially because the authors also found that this kind of information has a strong and mainly negative impact on the mental well-being of individuals with endometriosis (Arena et al., 2022, p. 103).

An interesting aspect of social media in relation to health communication is its potential to build online communities. Lindgren (2022) defines online communities as "groups of individuals who interact around a common interest, where the interaction is mediated or supported by internet technology" (p. 98). A classic example of online communities is Facebook groups, which are devoted to special interests or topics (Lindgren, 2022, p. 97). Many Facebook groups form around topics related to health and disease. In this context, these communities can be groups of patients, people who suspect they are affected by a disease, or people who have someone affected in their immediate surroundings. Importantly, the digital sphere can foster "relationships that would never have come to be in 'real life'" (Lindgren, 2022, p. 84). In some online communities, users can, depending on the platform's features, remain anonymous and use this anonymity as a "protective cloak" (Lindgren, 2022, p. 84). This often encourages people to take greater risks in self-disclosure and communicate more openly (Lindgren, 2022, p. 84), which can be especially valuable when discussing sensitive health-related information. However, Facebook is a non-anonymous service and actively requires identity confirmation (Lindgren, 2022, p. 89). Facebook groups, however, have a feature that, when enabled by group admins, allows members to post anonymously, hiding the user's identity from other group members.

Lewis and Lewis (2015) argue that "online communities provide an important arena for health communication driven by communities themselves" (p. 147). Through a form of "crowd-sourcing", these spaces enable people with similar health conditions to share personal experiences of coping and recovery, discuss healthcare options, and exchange practical information (Lewis and Lewis, 2015, p. 138). In the context of stigmatized and often silenced conditions such as endometriosis, online communities may therefore provide important spaces for recognition, validation, and open communication. Robvais (2020), for example, demonstrates this in her discussion of people living with Sickle Cell Anemia, showing how patients use online spaces to advocate for their voice and visibility. The author highlights the need for and value of online communities, because "sickle warriors learn through various websites how to perform for pain relief, where to find the most comprehensive care, and who will believe their narrative" (Robvais, 2020, p. 10).

Individuals with endometriosis often turn to online communities (Bologna et al., 2024). Sbaffi and King (2020) showed that those affected turn to "online peer-to-peer information exchange" because comprehensive, reliable information about endometriosis is still lacking (p. 387). Online communities facilitate this kind of exchange. The communities are valuable to

individuals affected by endometriosis, since they “help [members] to interpret their experiences, feelings and emotions” (Culley et al., 2013, p. 636). The groups are used for information and support (Culley et al., 2013; Senyel, Boyd and Graham, 2026).

The literature discussed in this subchapter suggests that participatory health communication emerges, in part, as a response to communicative absence and institutional invisibility.

# 3 Methodology

## Methodological Approach

This thesis adopts a qualitative case study design. Qualitative research positions the researcher as an "interpretive subject" who seeks to "interpret the interpretations that individuals and groups have of themselves and their communications" (Jensen, 2012, p. 266). Such an approach allows the researcher to 'read between the lines' and explore underlying meanings and nuances that may be overlooked in quantitative analysis. As outlined earlier, this thesis is grounded in a social constructivist perspective, making an interpretative approach particularly suitable for examining how such constructions are produced, negotiated, and understood.

The case study design allows for in-depth engagement with a specific example, generating context-dependent knowledge essential for understanding social phenomena (Flyvbjerg, 2001). While the study of concrete cases does not exclude empirical generalizations (Flyvbjerg, 2001, p. 136), case studies do not seek to produce ultimate, unequivocally verified knowledge, but rather contribute to the ongoing scholarly and social dialogue (Flyvbjerg, 2001, p. 139). In this sense, "the task of phronetic social science is to clarify and deliberate about the problems and risks we face and to outline how things may be done differently" (Flyvbjerg, 2001, p. 140). Within this study, endometriosis serves as such a case, illustrating broader societal issues, including the silencing of invisible chronic disease and the marginalization of women's health concerns. By examining this concrete example in depth, the study generates context-specific insights that can subsequently inform more abstract reflections and discussions. As discussed in *Chapter 2.1*, knowledge, power, and epistemology are closely interconnected. Consequently, this thesis adopts a feminist standpoint approach and intentionally centers marginalized voices that have long been disregarded in scientific research.

## Qualitative Focus Groups

A central aim of this study is to foreground the voices of individuals affected by endometriosis. For this reason, an interview-based approach was considered appropriate. While individual interviews were initially considered, focus groups were ultimately chosen as the primary method of data collection for several reasons.

Hansen and Machin (2019) suggest that participants often "open up" more in focus group settings (p. 307). Given the sensitive nature of the topic, a group setting encouraged open discussion by fostering a sense of shared understanding through participants' shared experiences and contexts. In addition, focus group discussions rely on interactions to generate

insightful data (Morgan, 1997, p. 15). As Morgan and Krueger (1993, cited in Morgan, 1997, p. 15) note, "the comparisons that participants make among each other's experiences and opinions are a valuable source of insights into complex behaviors and motivations". In this sense, focus groups create a dynamic setting in which meaning is actively co-constructed. This differs from individual interviews, where the researcher typically maintains a more distant role and limits their influence on the interview process. While such distance can help reduce researcher interference, it also means that participants engage with sensitive topics largely without interactional support or feedback. In a focus group discussion, however, participants have the opportunity to respond to each other. They can ask questions, give answers, express agreement and disagreement, and elaborate on shared experiences. As Morgan (1997) observes, "participants in focus groups often say the most interesting aspect of their discussions is the chance to 'share and compare' their ideas and experiences" (p. 20). Such interaction may also provide validation and emotional support in ways that are more difficult to achieve in one-to-one settings. According to Morgan (1997), these group dynamics "reveal aspects of experiences and perspectives that would be not as accessible without group interaction" (p. 20). For these reasons, focus groups appeared particularly well suited to discussing endometriosis among individuals with lived experience of the condition.

Focus group sizes can vary considerably, ranging from small groups to as many as 20 participants (Morgan, 1997, p. 43). According to Morgan (1997), the purpose of a study should determine the group size. In this present study, small groups were intentionally chosen, with each group consisting of two to three participants. Given the sensitive nature of the topic, small groups were expected to create a more comfortable environment for participants to share personal experiences. Furthermore, the study prioritizes in-depth insights into individual perspectives, requiring sufficient time for each participant to elaborate on their experiences. Smaller groups facilitate more detailed discussions and allow participants greater space to tell their stories (Morgan, 1997, p. 42). Morgan (1997) further notes that small groups "work best when participants are likely to be both interested in the topic and respectful to each other" (p. 42). Given that participants self-selected into a study on endometriosis and share similar lived experiences, it was anticipated that they would be both engaged with the topic and respectful toward one another.

**Recruitment and Sample**

The study employed a combination of convenience and 'snowball' sampling. Participants were recruited through multiple channels to enhance diversity within the sample. First, the online

advertisement for participation was shared within the researcher's social circles. Second, physical posters distributed throughout Lund were intended to draw attention to the study. Third, participants were recruited through Facebook support groups. Facebook showed particular promise, as it remains the most popular social media platform in Sweden (Statista Research Department, 2026), and its group function is commonly used for a variety of purposes, including topics related to lifestyle and health. Many of these groups are restricted, requiring users to request access and obtain administrator approval before viewing the content, which makes them less accessible. Using the Swedish term for endometriosis ("endometrios"), five relevant support groups were identified (see *Appendix A*). After receiving approval to join the groups and consulting with the administrators, a recruitment post was shared within the groups. Recruitment posts were deliberately written in an accessible and informal tone to reduce barriers to participation. All three recruitment strategies proved effective.

The study relied on participants' self-identification of suspected endometriosis. A formal medical diagnosis was intentionally not required due to the well-documented issue of diagnostic delay. In addition, the researcher intentionally chose to trust participants' accounts of suspected endometriosis, thereby approaching the issue differently from healthcare contexts in which individuals are often expected to "prove" their symptoms and experiences. Additional inclusion criteria required participants to be at least 18 years old and to have lived in Sweden for a minimum of six months, ensuring a certain familiarity with the country's culture and healthcare system.

The focus groups were offered both in person in Lund and digitally via Zoom. This approach ensured that place of residence did not become a barrier to participation and enabled individuals from across Sweden to take part in the study. The combination of diverse recruitment strategies and both digital and in-person participation also helped address the issue of purposively selected sample "bias" discussed by Morgan (1997, p. 35), by enabling a wider range of experiences and perspectives to be included.

The final sample consisted of ten participants across four focus groups: two online groups with two participants each and two in-person groups with three participants each. The digital focus groups had initially been planned with three participants each, similar to the in-person groups, but in both cases, one participant canceled at short notice. The groups were nevertheless conducted as planned, and the smaller group size did not appear to affect the discussions. It was further decided to conduct two groups in each setting (online and in person), rather than combining participants into one online and one in-person group, to allow for comparison across

settings. This decision was informed by Hurst's (2023) suggestion that "putting all your eggs into a single focus group basket is not a good idea" (158).

The four focus groups, with a total of ten participants, were conducted between 23 and 27 March 2026. Their durations ranged from 1 hour 21 minutes to just over 2 hours, resulting in a total of approximately 6.5 hours of recorded material. The discussions were conducted in English, which was a second language for all participants, including the researcher. However, this did not appear to significantly affect the discussions.

***Table 1**: Overview of Sample*

| Pseudonym | Age | Gender | Nationality | Region of Residence | Profession | Education Level | Focus Group (format) |
|---|---|---|---|---|---|---|---|
| Elin | 45 | Female | Swedish | Stockholm | Tech Product Owner & Delivery Lead IT | Post-Secondary Education | #1 online |
| Clara | 38 | Female | Swedish | Värmland | *currently not working due to pain* | Master's degree | #1 online |
| Jules* | 24 | Non-binary | French | Skåne | Waitress | Master's degree | #2 in-person |
| Miriam | 21 | Female | Swedish | Skåne | Student | High School | #2 in-person |
| Elise* | 23 | Female | Swedish | Skåne | Student | High School | #2 in-person |
| Osanna | 45 | Female | Russian | Skåne | *currently not working due to pain* | Master's degree, MBA | #3 in-person |
| Nora* | 25 | Female | Finnish | Skåne | Barista | Master's degree | #3 in-person |
| Elvira | 25 | Female | Swiss | Skåne | Student | Bachelor's degree | #3 in-person |
| Sara | 29 | Female | Swedish | Jämtland Härjedalen | Certified Nursing Assistant | High School | #4 online |
| Lola | 34 | Female | Slovak | Stockholm | Student | High School | #4 online |

* Suspected Endometriosis

An overview of the sample is provided in *Table 1*. Seven of the ten participants had received a medical diagnosis of endometriosis, while three suspected having it. Five participants were Swedish, while the remaining five had other national backgrounds. This international sample proved particularly insightful as endometriosis affects individuals globally. Participants with diverse national backgrounds were able to compare experiences in the Swedish context to those in other countries, thereby enriching the data. Nine participants identified as female, and one as non-binary. Limiting the study to women alone risks reinforcing narrow gendered assumptions about endometriosis and may inadvertently contribute to stigmatization. Since endometriosis

can affect anyone born with a uterus[3], gender-diverse perspectives are especially relevant and remain underrepresented in research (Eder and Roomaney, 2025). The sample provided coverage across a broad reproductive age range up to the onset of the natural menopausal transition, which typically occurs between 45 and 55 years of age, with an average age at menopause of 51-52 years (Polo-Kantola, 2008).

**Pilot and Discussion Guide**

The focus groups were conducted using a semi-structured discussion guide. Due to practical constraints, conducting a full pilot focus group was not feasible. Instead, a preliminary consultation was carried out with an individual from the researcher's personal network who has endometriosis. This consultation involved a detailed review of the interview guide and provided valuable feedback for refinement. The guide was subsequently adjusted accordingly. For example, the initial question *"If you could design the ideal information resources about endometriosis, what would they look like?"* was identified as potentially overwhelming for participants. Based on this feedback, a series of additional prompts was incorporated to support engagement with the question. Hurst (2023) recommends using such stimulus material to facilitate discussion (p. 158). The final focus group guide is available in *Appendix B*. While the guide ensured a degree of comparability across the focus groups, it remained flexible, allowing conversations to develop organically and enabling participants to introduce new topics. This flexibility is essential for capturing participants' perspectives in their own terms (Morgan, 1997, p. 40).

**Stimulus Materials**

In addition to prompts during the discussions, participants were provided with a set of stimulus materials before the focus groups[4]. They were asked to familiarize themselves with the materials beforehand, as these would form the basis of several discussion questions. The materials included a range of endometriosis awareness initiatives from different contexts.

From Sweden, participants were introduced to the campaign "Mycket Mensvärk Är Inte Okej"[5] by Socialstyrelsen, the Swedish National Board of Health and Welfare, and the digital exhibition "Pain Unseen – Narratives of Endometriosis" by Stockholm's Museum of Women's History. In addition, two Australian campaigns were included to provide an international

[3] To highlight this again: Endometriosis has, in rare cases, also been documented in people without a uterus or without menstruation (Jabr and Mani, 2014; Rei, Williams and Feloney, 2018).
[4] See *Additional References*
[5] "Severe Period Pain Is Not Okay" (translated by author).

perspective: “About Bloody Time” by the news website *news.com.au*, and “Take Your Life Off Hold” by the NGO *Endometriosis Australia*. The Australian context was selected for its pioneering role in endometriosis awareness, including the adoption of a National Action Plan for Endometriosis in 2018 (Australian Government Department of Health, 2018). Finally, the short film “This Is Endometriosis”, which won Best British Short Film at the 2026 British Academy Film Awards (BAFTAs), was also included.

**Analyzing the Data**

All focus group discussions were audio-recorded and subsequently transcribed in full (see *Appendix C* for a sample). In addition to spoken content, relevant verbal cues (e.g., laughter) and nonverbal cues (e.g., pauses and shoulder shrugging) were included in the transcripts to enrich the material for analysis.

The transcriptions were analyzed as textual data following Kuckartz’s (2014) methodological framework for qualitative text analysis, which combines hermeneutical considerations, principles of Grounded Theory, and ideas from qualitative content analysis. This approach is “rule-guided and intersubjective but also interpretive and creative at the same time” (Kuckartz, 2014, p. 36). The analysis adopted an abductive approach. While previous knowledge of the topic and existing literature informed the analytical process, particular emphasis was placed on inductive analysis following the logic of Grounded Theory. Rather than applying a fixed, predefined framework, categories were allowed to emerge from the data itself (Charmaz, 2006, p. 46). This inductive orientation was especially important because the study sought to explore participants’ lived experiences of endometriosis as they emerged in the focus group discussions and, therefore, aimed to remain open to unexpected themes and perspectives.

The coding process began with an initial phase of “open coding” (Kuckartz, 2014, p. 23). The transcripts were examined sentence by sentence, and segments that appeared analytically relevant were assigned preliminary codes. These initial codes were documented and organized in a mind map (see *Appendix D*). Following the open coding stage, the mind map served as a tool for connecting, renaming, consolidating, and organizing codes into broader categories (Kuckartz, 2014, p. 28). By grouping related pieces of data, recurring themes, contrasts, and relationships within the material could be identified.

Throughout the analytical process, memos and analytical reflections were continuously recorded in a notebook to document emerging findings and interpretations. These reflections later informed the development of the analysis chapter. The process also involved repeatedly

returning to the transcripts to refine interpretations and reconsider categories in light of new insights. This movement between coding, interpretation, and recoding reflects the iterative nature of qualitative research, which Saldaña (2013) describes as "cyclical rather than linear" (p. 58). This reflexive process supported ongoing hermeneutic interpretation and maintained awareness of the material's socially and interactionally constructed nature (Kuckartz, 2014, p. 36).

### Ethical Considerations

As health data is particularly sensitive, this qualitative study required careful attention to ethical considerations throughout the entire research process. Particular emphasis was placed on ensuring that participants were fully informed about the topic, aims, and intentions of the study before agreeing to participate, as "it is never appropriate to blindside participants with sensitive or threatening topics" (Hurst, 2023, p. 162). All participants provided informed consent and were made aware of their right to withdraw from the study at any time without consequence. The consent form included detailed information regarding data collection, storage, and the use of audio recordings. To further ensure confidentiality, participants were required to sign a confidentiality agreement (see *Appendix E* for both), thereby protecting their own privacy and that of the other group members (Hurst, 2023, p. 163).

Throughout the research process, all personal data was stored locally on a password-protected device, and identifying information was removed during transcription. All names used in this thesis are pseudonyms. Particular care was also taken to create a respectful and supportive discussion environment in which participants could share experiences at their own discretion.

### Methodological Reflections

The use of focus groups proved to be an effective methodological choice. Despite the small group sizes, the discussions were dynamic and generated rich data. Participants actively engaged with one another, often building on each other's experiences. Keeping the groups small facilitated in-depth contributions and allowed sufficient time for individual narratives. Even in the smallest groups, the discussions remained productive, suggesting that meaningful interaction does not depend solely on group size but also on participant engagement and topic relevance.

It is also important to reflect on my own positionality within this research project. As someone living with endometriosis, I occupied a dual position of both patient and researcher. This lived experience positioned me 'inside' the topic rather than approaching it as an external observer

and may have facilitated trust and openness within the focus groups. As Whelan (2007) notes, individuals with endometriosis are often guarded toward "outsiders", while her own "status as a woman with endometriosis enabled [her] to conduct extensive qualitative research within the community" (p. 960). Similarly, my lived experience may have made me more approachable and relatable.

While my personal familiarity with the topic provided valuable contextual insight, I placed great emphasis on not assuming expertise. Instead, I sought to remain curious and attentive, allowing participants' experiences and interpretations to take precedence. As emphasized by Holowka (2022), herself a researcher affected by endometriosis, it is crucial that "the experiences of these participants are at the forefront of this research" (p. 3). This principle aligns with Harding's (2008) notion of "sciences from below" (p. 114) and guided my approach throughout the study.

**Limitations**

While the methodological design of this study offers several strengths, it also comes with limitations. Although the study intentionally did not exclude gender-diverse perspectives in response to the lack of diversity highlighted in previous research (Eder and Roomaney, 2025; König and Meier zu Biesen, 2025), recruiting gender-diverse participants was not a specific focus of the sampling strategy. Consequently, only one of the ten participants identified as non-binary, while the remaining participants identified as female. In addition, the discussion guide did not include questions specifically designed to explore gender-related dimensions of living with endometriosis. As a result, while this study aimed to remain inclusive, it cannot provide substantial insights into the experiences of gender-diverse individuals with endometriosis. This thesis, therefore, joins existing calls for greater diversity and inclusivity in endometriosis research.

Another limitation concerns the cultural composition of the sample. Although the study included participants with different national backgrounds, the sample remained predominantly European. While these perspectives provided valuable insights into experiences within European healthcare and cultural contexts, the findings cannot be easily extended to non-European settings.

Furthermore, the study relied on a single-method qualitative research design and therefore did not incorporate methodological triangulation, understood as a "strategy for gaining several perspectives on the same phenomenon" (Jensen, 2012, p. 301). Nevertheless, focus group

discussions proved well suited to the aims of this thesis by generating rich, meaningful insights into participants' experiences and perspectives.

Finally, the stimulus materials presented during the focus groups were based on a selection that evolved throughout the earlier stages of the research process. While the materials were chosen to provide a diverse and multifaceted overview of endometriosis awareness efforts, the selection was not intended to be exhaustive, and other examples could have been included. Different materials may have prompted somewhat different reactions and discussions among participants. Nonetheless, the selected stimulus materials provided a valuable basis for reflecting on broader questions of awareness, representation, stigma, and health communication.

# 4 Analysis

The analysis is divided into three sections corresponding to the research questions. The first two sections examine the case in greater empirical detail, while the third section broadens the discussion by considering the implications of the findings for silent diseases and health communication more generally.

### Navigating Silence: Information, Support, and Media Use

Since awareness and knowledge of endometriosis remain limited, examining individuals' first encounter with the condition provides important insight into their endometriosis journeys. Participants often described spending many years believing that their experiences were normal. As Jules (FG 2) explained, "I just thought it was normal … because everybody says like, 'your period is really painful'". Similarly, Lola (FG 4) reflected, "I never looked for any information because I thought this is normal … I just don't want to buckle up and go at the world, I'm lazy or something". These accounts illustrate how pain is normalized and individualized, leading participants to dismiss or downplay their symptoms rather than interpret them as signs of a medical condition. This reflects what Hallström (2024) refers to as "pedagogy of pain", the widespread social belief that menstrual pain is normal and therefore not recognized as a symptom.

When participants began to recognize that something might indeed be wrong with their bodies, most described turning to Google to search for explanations for their symptoms. For many, this was their first encounter with the term endometriosis. Most participants explained that they came across the condition relatively quickly online. As Osanna (FG 3) reported, "I was doing a proactive search, and then the first thing that came up was endometriosis … It show[ed] all the symptoms. It [was] so clear". This suggests that active online information-seeking played a central role in participants' early understanding of their symptoms, which aligns with Sbaffi and King's (2020) finding that people with endometriosis are very active information seekers (p. 370).

Participants who did not first encounter endometriosis through online searches described learning about the condition through interpersonal networks or prior exposure in everyday life. Lola (FG 4), for example, reported first hearing about endometriosis from friends. Elvira's (FG 3) account stood out in particular, as she first became aware of the condition through her mother, who has endometriosis herself. Recognizing similarities between their experiences, Elvira's

mother explained the condition to her and actively encouraged doctors to investigate the possibility of endometriosis at an early stage. Elvira's story illustrates the significant role that awareness within one's social environment can play in identifying symptoms and facilitating earlier recognition of the disease.

Notably, none of the participants reported first learning about endometriosis through healthcare professionals. On the contrary, some explicitly emphasized that the condition was never mentioned in medical encounters until they raised it themselves. As Nora (FG 3) recalled:

> "Not once was endometriosis mentioned – ever, not in all the times that I was in so much pain, where I couldn't walk, where I was lying in bed for days. Not once was it mentioned until I started looking it up myself" (Nora, FG 3)

This absence of professional guidance reinforces the earlier finding that individuals are often left to identify and interpret their symptoms independently, highlighting a critical gap in the healthcare system's role as an initial source of information.

***Sources of Information and Support***

Participants described drawing on a wide range of sources for information and support throughout their endometriosis journey, both online and offline, reflecting a fragmented and exploratory process. When asked where they would look for information, Clara (FG 1) simply answered, "everywhere". Her response suggests that participants, rather than relying on a single authoritative source, navigated multiple channels simultaneously. This strategy of combining different sources to make sense of a widely unknown condition aligns with previous research on information-seeking behavior of women with endometriosis (Sbaffi and King, 2020; Senyel, Boyd and Graham, 2026).

The most commonly named source of information was the internet, or more specifically, Google. This aligns with findings from a scoping review by Senyel et al. (2025), which identifies the internet as the "most important access point for information" (p. 1). Online searches typically direct users to various websites, among which participants of all focus groups highlighted *1177*, the central national infrastructure for Swedish healthcare, as "everyone's go-to" (Sara, FG 4). Despite the site's widespread use, participants expressed strong dissatisfaction with the information it provides. Elin (FG 1) described it as feeling "dated 1980", and participants more broadly criticized the information as inaccurate, overly generalized, and too simplified. In short, they agreed that *1177*'s content is insufficient and outdated, leaving them skeptical, frustrated, and even outraged. This dissatisfaction is particularly striking given the expectations associated with such an authoritative national platform. As Elise (FG 2) noted,

while she initially felt she should be able to trust *1177*, her experiences have instead taught her to approach its content with caution. This tension points to a broader disconnect between institutional knowledge production and lived experience, in which official health communication loses credibility when it fails to reflect the realities of those affected.

Another source of information specified by participants was scientific studies. Elin and Clara (both FG 1) agreed that engaging with academic studies played an important role in their endometriosis journeys. Elin described staying informed through reading as her "main thing", particularly after realizing that her doctors had only limited knowledge of the condition. However, participants' perspectives on scientific research were not uniform. Lola (FG 4) described deliberately distancing herself from scientific studies after encountering research on social media that made her question the priorities of research. In particular, she referred to a study on the perceived attractiveness of people with endometriosis, which she found frustrating given the broader lack of funding and attention for the condition. As a result, she adopted a more protective stance towards information-seeking: "Not knowing is actually better to a certain degree". These accounts illustrate that while scientific studies can serve as an important source of information, they may also evoke critical reflection and even emotional resistance among those affected.

A more controversial resource among participants was generative AI tools based on large language models (LLMs), such as ChatGPT and Gemini. Five out of ten participants reported consulting AI for health-related concerns, while four others strongly rejected the idea. One participant had not used such tools but was not opposed to them in principle. Participants who engaged with AI tools described using them primarily for orientation and inspiration. For example, Clara (FG 1) appreciated how they "can nudge you in different directions", while Osanna (FG 3) found them useful "for initial information, if you completely don't know anything about the subject". Beyond informational purposes, AI tools were described as a source of emotional support. Lola (FG 4), for instance, explained that she sometimes uses them "to calm down" by discussing new symptoms or uncertainties. Sara (FG 4) recognized this behavior and related it to the benefit of "getting to process it out loud outside your head". However, she noted that she would typically turn to a close friend instead. These accounts illustrate how AI tools can mimic certain aspects of empathetic interaction while not replacing human relationships. This distinction aligns with Ma et al.'s (2026) finding that LLMs are used as complementary support rather than a replacement. Despite the perceived benefits, all participants demonstrated a critical awareness of AI's limitations in health-related contexts. As

Ma et al. (2026) observed, users often "maintained cognitive distance and enacted boundaries" (p. 1) when engaging with LLMs. Participants in this study reflected this by anticipating biases and articulating trust issues. Elin (FG 1), for example, instructed the AI tool not to "cherry-pick" information, while Clara (FG 1) explained that she would try to find scientific studies verifying the tool's responses, noting that "you can't really trust it, can you?". Participants who rejected LLMs altogether similarly cited a lack of transparency and uncertainty about information sources as key reasons for their skepticism.

Other resources mentioned more briefly in the focus groups included podcasts and books written by people living with endometriosis. Pop culture was rarely discussed, and when it was, participants did not primarily view it as a source of information but rather as a space for representation. In this regard, Lola (FG 4) expressed ambivalent feelings. While she appreciated seeing a character in a Netflix series with symptoms suggestive of endometriosis, she found the portrayal overly simplistic and superficial, which made the effort feel somewhat shallow to her. More broadly, participants repeatedly pointed to the limited visibility of endometriosis in mainstream media, including television, films, and series. This perception resonates with broader observations in the literature, which suggest that popular culture may offer visibility but often fails to provide nuanced or comprehensive understandings of women's health issues. As LeBlanc (2025) notes, "today's popular culture provides useful but incomplete information about critical women's health issues" (p. 94).

Social relationships emerged as an important resource for both information and support. Parents, particularly mothers, were frequently described as key points of contact. Since symptoms often appear at a young age, many participants reported first turning to their mothers. As mentioned earlier, Elvira (FG 3) received both information and strong support from her mother, while Miriam (FG 2) described her parents actively advocating on her behalf during medical encounters. However, these experiences were not universal. Some participants reported reaching out to their mothers but being dismissed, often due to a lack of awareness. In such cases, broader societal stigmatization of menstruation and endometriosis contributes to the normalization of pain, leading mothers to interpret severe symptoms as typical and not requiring further investigation. This, again, reflects what Hallström (2024) describes as "pedagogy of pain", in which menstrual pain is normalized and expected to be endured. In addition, a lack of personal experience with similar symptoms could result in reduced empathy or understanding. As previous research suggests, menstrual stigma is associated with increased self-stigmatization and reduced willingness to engage in conversations about menstruation (Eitze and Reinhardt,

2025). At the same time, interactions within social networks can be very eye-opening. Comparing experiences with friends often prompted participants to question their own assumptions about what is "normal". Elise (FG 2), for example, reflected that she had "gaslit" herself into believing that her symptoms were typical, thinking, "This is fine. This is normal because it is normal for me" until others challenged that perception by responding, "This is not good at all". However, such exchanges depend on a willingness on all sides to openly discuss menstruation and related health issues. Lola (FG 4) recalled that conversations about periods were often met with shame among her peers during her adolescence and noted that she still finds herself encouraging others to speak more openly about these topics today. Taken together, these accounts illustrate how social relationships can both reinforce and disrupt the normalization of symptoms, thereby playing a crucial role in both sustaining and challenging the silence surrounding endometriosis.

The final resource mentioned by most participants was social media. Platforms such as Instagram, TikTok, Facebook, and Reddit played a central role in their endometriosis journeys. Participants described using these platforms for a variety of purposes. On the one hand, they turned to social media to seek information. Elise (FG 2), for example, explained how, after suffering from severe nausea, she learned through Reddit threads that this symptom could be linked to endometriosis. Jules (FG 2) shared a similar experience, describing TikTok as a constant companion in their journey, using it to research and verify symptoms. This aligns with Holowka's (2022) findings, which show that individuals with endometriosis use social media to understand, experiment with, and navigate their symptoms (p. 1). In this regard, participants highlighted the value of testimonials shared by others with endometriosis. As Jules (FG 2) explained:

> "It's so good to have people that have the experience and all of the weird symptoms that you might have and all of the specifics. And they're real, and they're telling you that that's what they've been through … it's nice to have a face on it" (Jules, FG 2)

Through testimonials, social media offers validation and comfort to those affected. Participants emphasized that seeing others with similar experiences helped them feel less alone and reassured them that their symptoms were real, which could relieve anxiety. These accounts suggest that individuals with endometriosis often struggle with self-doubt and rely on external validation to make sense of their experiences. This dynamic can be understood in light of Goffman's (1986) argument that stigmatized individuals internalize dominant standards of normality and, in doing so, may discredit their own experiences.

In this context, the support provided through social media closely resembles offline support discussed earlier, such as conversations with friends or family members, while also extending beyond it. As Lindgren (2022) argues, social relationships are not new, but digital media allow them to stretch "beyond the local realm" and significantly amplify the reach of people's connections (p. 108). This expanded connectivity enables individuals to access a broader range of experiences and perspectives than would be possible within their immediate social environment. This is consistent with research showing that people with endometriosis actively seek interaction with others affected, both online and offline, in order to access information and emotional validation (Senyel, Boyd and Graham, 2026, p. 12). In addition, testimonials were often perceived as offering more holistic and nuanced perspectives than official sources, serving as an alternative to the insufficient information found on platforms such as *1177*. As a result, testimonials emerged as one of the most trusted sources of information. This finding is supported by previous research indicating that individuals with endometriosis often regard others with lived experience as their most useful and valuable source (Culley et al., 2013, p. 636). Sara (FG 4), for example, described people with endometriosis as "a way more reliable source" than online searches or official health authorities, while Elvira (FG 3) emphasized that she "trusts that [they are] honest". Elise (FG 2) similarly argued that information from those with lived experience "is always more accurate", adding "unfortunately", thereby implicitly criticizing official health communication.

More broadly, participants engaged with endometriosis content on social media produced by both laypeople and professionals, such as doctors and nutritionists. Elin (FG 1), for example, described following an Instagram account that shares surgical footage of endometriosis cases, offering insights into the extent and complexity of the condition. Other forms of content, such as memes, were also mentioned as coping mechanisms. Miriam (FG 2) explained that memes helped her deal with chronic pain, suggesting that humorous content can provide a sense of recognition and emotional relief.

Beyond the benefits of social media use, participants also drew attention to the algorithmic structures that shape what content is made visible on social media platforms. As Jules (FG 2) noted:

> "I feel like I see it everywhere now, but I'm in the bubbles, you know. The algorithm now, it just knows. So, obviously, it's catered to me, so I see a lot of it … If you don't look for it – like, some of my close friends didn't really know what it was" (Jules, FG 2)

This observation highlights that while social media can be highly valuable for those actively seeking information, its reach remains limited and tends to be rather accidental. Content tends to circulate within algorithmically curated "bubbles", meaning that awareness efforts on these platforms may primarily reach those who are already engaged with the topic. This reflects König and Meier zu Biesen's (2025) argument that health-related content on social media tends to circulate among already engaged audiences, limiting its potential to foster broader public awareness (p. 2).

A particularly ambivalent form of social media use emerged in participants' accounts of Facebook groups. These groups were described as both supportive and overwhelming. On the one hand, they provide a space to learn from others and exchange experiences with those who understand the condition. Lola (FG 4) noted that it can be comforting to have "a place to share", and Sara (FG 4) described them as a way to gain "recognition of not being alone". On the other hand, participants emphasized the emotional burden associated with these spaces. Lola (FG 4) explained that the content shared in such groups is overwhelmingly negative, which can become "too much" and lead users to distance themselves. This contradicts the underlying assumption in the health information-seeking literature that seeking information is often desirable and central to health and illness behaviors (Lambert and Loiselle, 2007, p. 1015), as some people become overwhelmed and feel the need to distance themselves. Sara (FG 4) described how constant exposure to such content turned the groups into a persistent reminder of her disease:

> "Right now, it's been beating me over the head a lot ... It's just being remembered that you're sick, and the more you tell yourself that, the sicker you get somehow … I'm trying to find a good middle ground between accepting where I am, but also not making myself sicker by mulling over it so constantly" (Sara, FG 4)

Elin (FG 1) also reported negative experiences, including being criticized by others for sharing her experience with alternative treatment approaches, which led her to engage with such groups only intermittently. Similarly, Osanna (FG 3) described feeling discouraged and hopeless after reading negative testimonials in groups. Taken together, these accounts reveal a fundamental ambivalence in participants' engagement with social media. While it offers valuable information, validation, and community, it can also become overwhelming and emotionally taxing. Participants thus described navigating a constant tension between the benefits of connection and the need to distance themselves from an "overflow of media" (Osanna, FG 3).

### *Emotional Burden and the Turn to Media in a Context of Silence*

Throughout the focus group discussion, it became evident that participants experienced a wide range of emotions in relation to their endometriosis journey. These emotions were

predominantly negative, including frustration, hopelessness, helplessness, discouragement, and humiliation.

Many of these emotional responses were closely linked to participants' experiences within the healthcare system. Participants reported numerous negative encounters with medical professionals, ranging from long waiting times for appointments and feeling unheard to instances of outright dismissal and patronizing behavior. Several participants described feeling they had to "prove" both the existence and the severity of their condition, placing considerable emotional strain on them. In this regard, participants' accounts resonate with Foucault's conceptualization of the medical encounter as a site of unequal power relations, in which medical authority shapes what is recognized as legitimate knowledge (Lupton, 2012, pp. 23–24). While this thesis also highlights the potential of medical encounters at a later point, the findings presented here suggest that, in the context of endometriosis, interactions frequently develop in ways that reflect the asymmetries described by Foucault. Notably, participants' diverse national backgrounds did not appear to significantly alter these experiences, suggesting that such challenges are not confined to a specific healthcare system but may reflect a broader, transnational pattern. Similar criticism toward healthcare systems has also been observed in social media-based research, where negative experiences and dissatisfaction with medical care emerged as a central theme in discussions of endometriosis (Neugebauer et al., 2025, p. 5).

A recurring issue raised by participants was the perceived lack of knowledge among healthcare professionals. This manifested in inadequate examinations, overlooked symptoms, misdiagnoses, and an inability to answer basic questions. Osanna (FG 3) linked this "lack of information or competence" to dismissive behavior. Many participants described having consulted "infinite" (Sara, FG 4) doctors in search of one who would take them seriously. Even when they felt heard, participants often encountered quick-fix solutions or professionals who seemed to have reached the limits of their knowledge. Miriam (FG 2) underscored, "<u>They</u> need to know. We shouldn't have to be the ones educating them" [emphasis in audio, added by author]. These accounts align with previous research indicating that clinicians' awareness and education about endometriosis are often perceived as insufficient or outdated (Sbaffi and King, 2020, p. 385). In addition, studies of social media discourse have identified a notable level of distrust toward healthcare providers, with nearly a quarter of TikTok videos on endometriosis explicitly expressing such concerns (Wu et al., 2023).

These accounts highlight a broader pattern: individuals with endometriosis are often compelled to become their own health advocates, taking on responsibility for navigating and interpreting

their condition. This places a significant burden on those affected and is frequently accompanied by a sense of being left to one's own fate. As Osanna (FG 3) put it, "This is your disease, this is your problem". This already indicates the central role of health communication.

Negative experiences with healthcare professionals, such as feeling dismissed or not taken seriously, often led to feelings of humiliation and discouragement, as established earlier. These emotional responses frequently prompted participants to turn to alternative sources of information. As Osanna (FG 3) described:

> I couldn't believe nothing is wrong with me – 'Oh, just take antidepressants, and you will be fine' – This approach was really gaslighting and humiliating, you know, as if you're just imagining these things. And then I started looking online" (Osanna, FG 3)

Similarly, Jules (FG 2) explained how acute moments of distress led them to seek support through social media:

> "Sometimes I'm having like a really bad episode, and they're like, 'well, you can have an appointment next week', and I'm like, okay, but I haven't slept in a week. Can you help me now? Yeah, and then that's when I turn to social media … to just find … anything. Even if it's not something to soothe the pain … even if it's just testimonies, that's nice" (Jules, FG 2)

Interestingly, participants did not raise concerns about misinformation on social media, despite its prominence in literature (e.g., Arena et al., 2022). This suggests that, from their perspective, the content's emotional and experiential value may outweigh concerns about its accuracy.

***Between Institutional Gaps and Participatory Practices in Health Communication***

This first part of the analysis highlights several central patterns in participants' engagement with information and support. Most notably, it reveals a significant lack of effective top-down health communication. Participants rarely referred to such efforts, including public campaigns or mainstream media, and when they engaged with official platforms (e.g., *1177*), these were often perceived as insufficient, outdated, and overly generalized. This suggests that formal health communication fails to provide meaningful guidance or recognition for those affected by endometriosis.

In contrast, participatory forms of health communication, particularly through social media, played a far more central role. These bottom-up sources were described as valuable for accessing experiential knowledge, validation, and emotional support. However, they do not reach everyone and often require prior awareness or active searching. In addition, participants' accounts show that such sources can be overwhelming and emotionally demanding, highlighting their ambivalent nature.

Taken together, these findings indicate that individuals with endometriosis must navigate a fragmented landscape of information and support. Rather than relying on structured, accessible institutional communication, they are frequently left to piece together knowledge from scattered, informal sources. Moreover, media use emerges not only as a means of accessing information but also as an emotionally driven response to unmet needs within the healthcare system and gaps in institutional health communication.

**From Silence to Visibility: Participants' Perspectives on Health Communication**

This section examines how participants perceive and reflect on the role of media and health communication in shaping the visibility, recognition, and understanding of endometriosis. It explores how insufficient visibility affects individuals with endometriosis, before turning to participants' perspectives on how health communication could be improved.

***The Vicious Circle of Silent Suffering***

While participants emphasized the importance of visibility created through health communication, their accounts also revealed how experiences of invisibility, dismissal, and misunderstanding continue to shape everyday life with endometriosis.

As established, individuals with endometriosis often suffer invisibly as their symptoms are not externally observable. When individuals attempt to make their condition visible, they are frequently met with disbelief, misunderstanding, or stigmatization. Such responses can have profound effects. Participants described how these external perceptions become internalized, leading to self-doubt and, in some cases, the adoption of stigmatizing labels. This process reinforces isolation, discourages those affected from seeking medical care, and contributes to further invisible suffering. This thesis conceptualizes this dynamic as the *"Vicious Circle of Silent Suffering"* (*Figure 1*).

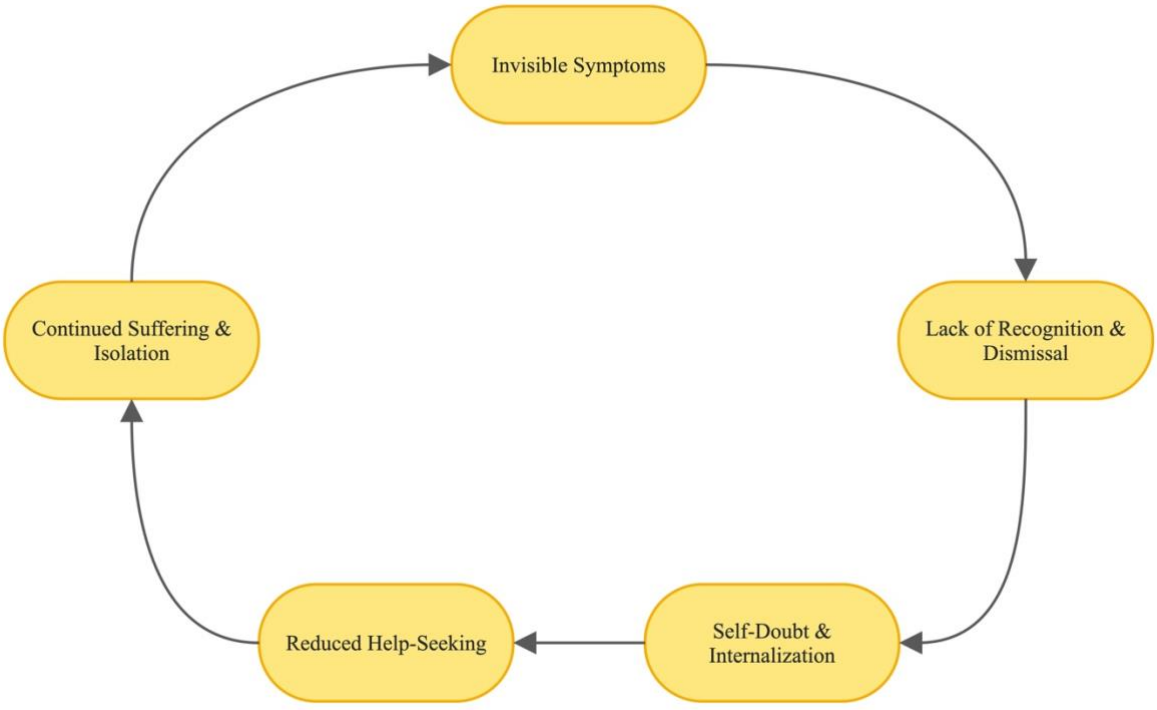
The internalization becomes evident in participants' accounts. Nora (FG 3), for example, stated, "I feel a little bit ridiculous going to the emergency room because of cramps". Similarly, Lola (FG 4) reflected, "I still feel like I'm making half of this shit up, even though I've been through surgery, I've been through medication, I've seen doctors, I still feel like … aren't you just … exaggerating?".

Osanna (FG 3) highlighted how the invisibility leads others to underestimate the severity of the condition, "We look good, healthy, right? What could possibly be wrong?". At the same time, she pointed to a coping strategy of those affected that reinforces this dynamic: "We usually try

to hide and conceal that … but then they don't realize how much you suffer … even the doctors, they don't take you seriously" (Osanna, FG 3). This reflects what Hallström (2024) refers to as the "beautiful is healthy" stereotype, according to which looking good is associated with feeling good (p. 15).

Hallström (2024) further argues that a lack of recognition and support can affect individuals' "sense of truth" (p. 20). She explains that prolonged exposure to disbelief and dismissal intensifies self-doubt and undermines self-confidence, making it increasingly difficult for individuals to seek medical attention or assert the legitimacy of their experiences. This dynamic is also evident in the present study. Conversely, a diagnosis can represent a "critical turning point" (Hallström, 2024, p. 14), as it provides validation that individuals' experiences are legitimate and not "in their head". In this way, recognition has the potential to weaken or interrupt the *Vicious Circle of Silent Suffering*.

***Figure 1:*** *The Vicious Circle of Silent Suffering*




***Source:*** *Author's own Conceptualization based on Focus Group Findings.*

The dynamic highlights the importance of health communication that promotes visibility and recognition. As participants' accounts suggest, increased visibility can validate individual experiences and help disrupt cycles of self-doubt and silence.

Participants' accounts further highlight that experiences of disbelief are not limited to the healthcare system, as already established, but extend into everyday social life. They described feeling misunderstood, stigmatized, and dismissed by both medical professionals and the broader public. These experiences reflect a central tension often associated with stigma, namely the struggle to seek recognition and understanding while resisting being defined by one's condition (Goffman, 1986). As Lola (FG 4) explained, "I don't want the disease to define me … sometimes I might cancel plans … and it doesn't mean that I hate [my friends]". This tension contributes to feelings of insecurity and reinforces the need for social recognition and compassion.

A striking finding in this regard was that participants across all focus groups, without prompting, drew comparisons between endometriosis and cancer. These comparisons were made both medically and socially. On a medical level, participants mentioned similarities in disease behavior, which have been confirmed by research (Ellis and Wood, 2026). On a societal level, the comparison served a different function. Participants highlighted that cancer is widely recognized, researched, and funded, whereas endometriosis remains comparatively invisible. As Sara (FG 4) expressed:

> "I'm definitely at the stage now where I wish to God it was cancer. Because cancer is researched. And cancer – people know what that is, you don't have to explain it to anyone. There are so many treatment plans" (Sara, FG 4)

Such comparisons reflect a perceived inequality in recognition, resources, and legitimacy. They express a sense of injustice and underline participants' desire for greater awareness, understanding, and institutional support. In addition to cancer, participants also compared endometriosis to diabetes. While cancer was mostly used as a reference point for visibility and research funding, diabetes was invoked as an example of normalized understanding in everyday life. Participants referred to this as the "diabetes treatment" (Sara, FG 4), indicating a desire to be treated with a similar level of recognition and acceptance, where their condition is taken seriously without requiring constant explanation or justification. Ultimately, this reinforces the central argument of this section: increased and effective health communication can significantly impact the lived experiences of individuals with endometriosis.

### *Toward More Effective Health Communication*

Building on the challenges identified above, participants' accounts offer valuable insight into how health communication efforts could be designed more effectively.

*Identifying Target Audiences*

A central consideration was the audience of such initiatives. Participants consistently emphasized adolescents as a primary audience, understood in health communication terms as the group whose attitudes or behaviors are intended to change (Lewis and Lewis, 2015, p. 85). They highlighted that endometriosis often begins shortly after the first period, yet remains underdiagnosed, which can lead to disease progression and long-term complications (Gupta et al., 2018; Simone, 2025). Osanna (FG 3), for example, stressed that early recognition could "save[…] lives", describing education as "a must" in school. Similarly, Lola (FG 4) reflected on her own experience, noting that "if I had heard about that endometriosis even exists when I was a teenager, who knows where I would be now".

Importantly, participants emphasized that the information should be addressed to teenagers both with and without a uterus to reduce the stigma surrounding menstruation and related health conditions. Miriam (FG 2) criticized the gendered structure of sex education, recalling that "boys were taught about sex, and we were taught about periods", arguing that such separation reinforces taboo. Osanna (FG 3) similarly highlighted that educating those without a uterus could foster greater empathy and understanding, reducing the tendency to dismiss individuals with endometriosis symptoms as "moody or depressed".

However, participants acknowledged that adolescents may be a difficult audience to reach. As Sara (FG 4) noted, "it's so awful being a teenager – you want to be normal. So, no one wants to identify with this off-branded illness that they've never heard of". For this reason, participants also emphasized the importance of secondary audiences, meaning groups who are likely to influence the primary audience (Lewis and Lewis, 2015, p. 85). These include parents, guardians, and teachers, who are often the first point of contact when adolescents seek advice or support. Sara (FG 4) explains:

> "If you can't get the young teenagers to read about it, you need someone in their sphere to … have heard about it. So, if it comes up, ever, someone can sort of meet them with 'have you heard about this?'" (Sara, FG 4)

School nurses were also identified as key intermediaries, bridging the gap between adolescents and the healthcare system. In addition to adolescents, participants repeatedly identified healthcare professionals as a primary audience. Many emphasized the need for improved education and training, particularly in early recognition and referral. Elise (FG 2) described this as "mostly where the information is needed". Participants stressed that all healthcare

professionals should possess at least basic knowledge of endometriosis, enabling them to recognize symptoms and appropriately guide patients. As Miriam (FG 2) explained:

> "We should be able to go to our normal doctor, and he would be like, 'oh it could be this thing, I will send you to a specialist'. Not that they need to treat it, but they have to know about it" (Miriam, FG 2)

Finally, participants also pointed to the general public as an important secondary audience. This refers back to the earlier argument that increasing awareness among the wider population was seen as a way to foster understanding, reduce stigma, and enable earlier recognition of symptoms within social networks. Greater public awareness could encourage supportive responses and help individuals seek appropriate care more quickly.

Taken together, these findings suggest that participants view effective health communication as a multi-level effort that targets not only those directly affected, but also the broader social and institutional environments in which they are embedded. This aligns with socio-ecological perspectives in health promotion, which emphasize that communication should facilitate change across multiple levels, including interpersonal, community, and societal contexts (Lewis and Lewis, 2015, pp. 7–8). These suggestions reflect participants' awareness that improving outcomes requires not only individual knowledge, but structural change in how endometriosis is recognized and communicated.

*Defining Communication Content*

When discussing the content of health communication regarding endometriosis, participants offered a range of suggestions, with three key themes emerging consistently.

First, participants criticized the limited representation of symptoms in many existing health communication efforts, particularly in top-down communication. Endometriosis is often primarily associated with painful periods or pelvic pain, yet even within this small sample, participants reported a wide variety of symptoms – far too many to list exhaustively. Participants emphasized the importance of reflecting the complexity of endometriosis in health communication. When representations focus too narrowly on specific symptoms, individuals whose experiences differ may fail to recognize themselves and therefore delay seeking help. As Sara (FG 4) explained, "it doesn't take much to read a symptom that you don't identify with to go like, okay, then it can't be that. And then you … distance yourself from it again". This dynamic contributes to the *Vicious Circle of Silent Suffering* identified earlier. Closely related to symptom diversity is the condition's unpredictable nature. Sara (FG 4) illustrated it vividly: "Imagine someone walking around pushing a gun into your back all the time, and you just have

to trust them not to pull the trigger". Overall, participants stressed that communication should better reflect how the condition, in its many forms, affects quality of life.

Second, participants expressed ambivalent views on how the severity of the disease should be communicated. In particular, the use of "worst-case scenarios" was debated. For example, Nora (FG 3) and Elise (FG 2) described feeling intimidated by portrayals of extreme suffering, which prompted comparisons with their own experiences and triggered self-doubt. At the same time, others viewed such representations positively. Elvira (FG 3), for example, described these depictions as "very real", while Osanna (FG 3) argued that showing the full severity of the condition could potentially reduce stigmatization by building compassion. This highlights a tension between the risks and benefits of emphasizing severity in health communication.

Third, participants emphasized the need for greater nuance in health communication about endometriosis. This includes presenting a broader range of treatment options and acknowledging that experiences of endometriosis vary widely. Elin (FG 1), for instance, described how she has benefited from a ketogenic diet and expressed a desire for alternative approaches to be communicated more openly so others can explore them. Participants also stressed that communication should extend beyond diagnosis, as a diagnosis is not "the end goal", but rather "just the beginning again" (Miriam, FG 2). In addition, participants highlighted the importance of tailoring health communication to cultural and national contexts. Sara (FG 4), for example, described Sweden as "so stuck up and closed off … [where] you definitely don't talk about embarrassing things", underscoring how cultural context shapes stigma. This aligns with existing research emphasizing that health communication must consider the cultural and social context of its target audiences (Brann, 2024, p. 432). While communication has the potential to build compassion and reduce stigma, it must be carefully designed to resonate within specific cultural settings.

*Choosing Channels and Formats*

When discussing how health communication should be delivered, participants distinguished among channels and formats based on the intended audience.

As discussed, social media was perceived as most effective at reaching individuals who had already encountered endometriosis. Osanna (FG 3) suggested that a similar dynamic applies to online information more broadly: "If there is something somewhere on the website and you don't know what to look for, there is very little chance you will even end up finding it". While this may seem contradictory, given that many participants initially learned about endometriosis

through online searches, those encounters were typically the result of active information-seeking rather than passive exposure.

To reach individuals who have not yet encountered endometriosis, participants emphasized the potential of physical formats in public spaces. Suggested approaches included posters and leaflets in schools and healthcare settings. Miriam (FG 2) proposed placing advertisements on buses and at bus stops, an idea that received strong support within her group. Another powerful example of health communication in physical form was suggested by Osanna (FG 3): "What if we put information on every single pad or tampon?". This idea of pictorial health promotion on period products is reminiscent of cigarette packaging, where graphic warning labels have been shown to strengthen smokers' intentions to quit through fear appeals (Kees et al., 2010). While such tobacco control strategies rely on deterrence, the participant's suggestion indicates that packaging in the context of period products could instead serve informative and awareness-raising purposes, targeting those most likely to be affected. The idea aligns with existing literature on packaging as a strategic marketing communication tool. Packaging is not only functional but also serves as a channel through which companies can convey messages and values (Kiygi-Calli, 2019, p. 133). Integrating corporate social responsibility into such communication can be particularly effective, as it allows companies to connect social causes with their branding. Using period product packaging for health promotion can be understood as a form of "philanthropic marketing", where organizations link products to social issues while also pursuing economic goals (Thorne McAlister and Ferrell, 2002, p. 702). Research suggests that aligning business resources and competencies with societal needs can not only benefit communities but also positively influence financial performance (Thorne McAlister and Ferrell, 2002, p. 702). However, for such initiatives to be effective, they must be consistent with a company's mission, values, and resources (Thorne McAlister and Ferrell, 2002, p. 702). This makes period product companies particularly well-suited to promote endometriosis awareness, as the cause is closely related to their core products and target audience.

In addition to physical formats, participants discussed the role of television and popular culture. These were seen as effective channels for reaching a broad and diverse audience. As Nora (FG 3) noted, such formats can reach "a general audience – not just people who go looking for information, but anyone … watching TV". While participants expressed ambivalence toward existing portrayals of endometriosis in popular culture, often perceived as overly simplistic, they also recognized their potential influence. Literature suggests that when carefully designed, these portrayals can be highly influential. Entertainment and popular culture have been

described as a “powerful medium for cultural change” (Lewis and Lewis, 2015, p. 154). The concept of “entertainment-education” builds on this potential by integrating health messages into widely consumed media formats. Through this approach, health communication can reach broad and diverse audiences, as popular media is consumed across different social and cultural contexts worldwide (Lewis and Lewis, 2015, p. 154).

Overall, participants’ suggestions indicate that effective health communication requires a strategic mix of channels. While social media may primarily reach those already engaged with the topic, physical and mass-mediated formats have greater potential to reach previously unaware audiences. Participants’ proposals highlight the importance of embedding health communication in everyday environments, both physical and mediated, to reach individuals more easily.

***Balancing Bottom-Up and Top-Down Approaches in Health Communication***

Overall, participants argue for both participatory, bottom-up and formal, top-down approaches to effectively communicate endometriosis.

On the one hand, those affected were seen as having the agency to engage in participatory health communication. Lola (FG 4), for example, argued that this begins with destigmatizing both menstruation and pain. She emphasized that responsibility lies with everyone, urging people to “stop calling these things TMI [too much information]” and instead speak openly about them as they are “part of our life”. Similarly, some participants described individuals with endometriosis as potential “ambassadors” (Elin, FG 1), contributing to awareness through personal advocacy. Nora (FG 3) reflected that she had “started telling everyone who would listen”, emphasizing that such efforts can make a difference. Participants also pointed to the influential role of public figures. As Osanna (FG 3) noted, when celebrities speak openly about their experiences with otherwise silent conditions, it can prompt others to recognize their own symptoms. These accounts once again highlight the importance of testimonials as a form of participatory health communication that can increase visibility and challenge stigma. At the same time, participants emphasized that such efforts alone are not sufficient and require support from institutional actors. In this sense, participatory communication was seen as a way to draw attention to the issue and urge those in positions of power to take action.

On the other hand, participants stressed that awareness efforts must also be expert-driven and supported by formal institutions. As Elin (FG 1) put it, “things have to come a bit top-down”. Official health authorities were regarded as particularly important due to their perceived

credibility and influence. Participants frequently referred to the national health service *1177*, described as the "medical Google for Sweden" (Lola, FG 4), as a key actor in disseminating information. As Sara (FG 4) argued:

> "If people see it from them … they take it more seriously, they think it's an actual thing … Because that's government-approved. This is how the government gets out information about public health. That's how I want it to be [for endometriosis]" (Sara, FG 4)

This illustrates how institutional endorsement contributes to the perceived legitimacy of health information. Participants also highlighted the close connection between health authorities and governmental structures, emphasizing their responsibility to provide resources for large-scale awareness efforts. As Lola (FG 4) suggested, such initiatives should be approached strategically, "[like] a marketing campaign".

In addition, participants noted that top-down communication can influence the healthcare system itself. Increased public awareness may generate demand for information and care, thereby putting pressure on healthcare providers to improve their knowledge and responsiveness. As Sara (FG 4) argued: "The supply needs to meet the demand".

Finally, participants emphasized that relying solely on individual advocacy places a significant burden on those affected. As Osanna (FG 3) described, living with endometriosis is "so draining and exhausting", leaving individuals with limited capacity to continuously advocate for themselves. In this context, formal health communication can provide important structural support and reduce the responsibility placed on individuals.

To conclude this second part of the analysis, these findings highlight the need for an integrated approach to health communication that combines participatory and institutional efforts. While bottom-up communication plays a crucial role in increasing visibility and challenging stigma, top-down initiatives are necessary to ensure legitimacy, reach broader audiences, and provide structural support. As Elvira (FG 3) summarized, "It would be very important to talk about this disease on every platform possible".

### The Role of Health Communication in Shaping the Visibility of Silent Diseases

This chapter discusses what the case of endometriosis reveals about the role of health communication in shaping the visibility of "silent diseases".

### *The Triple Burden*

Throughout the analysis, it became evident that current health communication about the silent disease, endometriosis, is limited and insufficient. This thesis identifies three consequences of these shortcomings, conceptualized here as a *"Triple Burden"* carried by those affected.

First, individuals are forced to become **self-educators**. This includes independently discovering the disease, often due to insufficient knowledge among healthcare professionals. In addition, individuals must navigate a fragmented landscape of information sources, frequently relying on support from others affected. This process requires assessing the credibility of information amid incomplete and potentially misleading content. Through this demanding journey, some patients become self-taught "expert patients" (Sbaffi and King, 2020, p. 384), who in turn share knowledge and experiences with others. Elin (FG 1), for example, contributes to online patient communities by sharing insights on dietary changes that may serve as an alternative or supplement to traditional hormonal treatments.

Second, individuals affected by a silent disease are compelled to become **self-advocates**. Faced with disbelief, dismissal, and stigmatization, they must continuously assert the legitimacy of their condition. This involves not only confronting others but also managing internalized self-doubt. It often requires explaining one's symptoms to others who are unfamiliar with the condition. As Miriam (FG 2) described, "I've told all my friends about it … we talked in groups, and none of the others knew what it was". Similarly, Lola's (FG 4) concern about being misunderstood when canceling plans illustrates how individuals must repeatedly justify their experiences in everyday interactions. Self-advocacy also entails persisting in seeking medical attention despite recurrent negative experiences within the healthcare system. Nora's (FG 3) advice to others illustrates this ongoing struggle, highlighting how frustration and anger can become driving forces in the effort to be heard:

> "Keep going to the doctor. Keep telling them what's wrong … It does make a difference. And I think … the anger spurs you on. When nobody listens, and when nobody takes you seriously … it makes you want to go again, and want to go again, and tell them again. And keep doing what you can to make yourself heard … And as bad as it is … at least I know that I'm doing my best and prioritizing my own health" (Nora, FG 3)

However, this constant need to advocate for oneself is emotionally and physically demanding, particularly given the already limited energy of those affected.

Third, individuals are compelled to **compensate for gaps in formal health communication** by engaging in participatory communication. By sharing experiences in online communities or on social media, they help raise awareness and support others. While this can be empowering,

it also reflects a structural failure: when formal communication is lacking, participatory efforts shift from being supplementary and optional to becoming necessary.

***Communicating Silent Diseases: It Takes Both***

The analysis demonstrates that, in the context of a silent disease, participatory (bottom-up) health communication holds significant potential. User-generated content, particularly in the form of testimonials, plays a crucial role in validating experiences, providing emotional support, and offering nuanced perspectives. In this way, it contributes to breaking the silence surrounding the condition. However, participatory communication primarily reaches individuals who are already aware of the disease or actively seek information. As a result, those who are unaware, including individuals at risk, often remain unreached, and the disease remains silent to them. At the same time, the constant "overflow" of informal communication, often dominated by negative experiences, could become emotionally overwhelming and lead those affected to distance themselves from these spaces. This highlights the limitations of relying solely on bottom-up communication.

In contrast, formal (top-down) health communication is essential for reaching broader audiences. By targeting everyday environments, both physical and mediated, it can create widespread awareness. Examples include public campaigns, educational initiatives, and the integration into popular media formats through entertainment-education. Such approaches can play a crucial role in fostering understanding and compassion among wider audiences, thereby contributing to more open dialogue and reduced stigmatization. Importantly, top-down communication can also alleviate the *Triple Burden* placed on individuals.

Participants attributed particular influence to communication disseminated by official health authorities supported by government institutions, as these actors are perceived to have both extensive reach and high credibility. However, for such communication to be effective and trustworthy, it must accurately reflect the condition's complexity and ensure nuanced and responsible representation.

This highlights an additional key finding of this thesis: effective health communication for silent disease requires integrating bottom-up and top-down approaches that combine lived experience with structural reach and legitimacy. The voices of those affected, thereby, represent a powerful resource. Incorporating lived experiences not only enhances authenticity but also prevents harmful misrepresentations that may discourage individuals from seeking care. Campaigns such as #1in10 illustrate how this integration can be achieved (Stanek et al., 2023).

### *A Mismatch That Matters*

A final, but central, issue emerging from this analysis concerns the relationship between public awareness and the healthcare system. While health communication encourages individuals to seek medical care, participants repeatedly described a mismatch between these messages and their actual experiences in healthcare systems. Despite being encouraged to seek help, they often face long waiting times, dismissal, and inadequate care. This creates a paradox: awareness initiatives direct individuals toward a system that is not sufficiently equipped to respond effectively. As one participant summarized, "The system is failing" (Osanna, FG 3). This discrepancy has significant consequences. Rather than alleviating uncertainty, it can intensify self-doubt and reinforce the *Vicious Circle of Silent Suffering*. As Sara (FG 4) noted, such experiences "just make[…] you feel worse".

This dynamic is also reflected in broader health communication research. Wakefield et al. (2010) emphasize that the availability of and access to relevant services are crucial for enabling individuals to act on media messages (p. 1268). In this light, participants' experiences suggest that, even when awareness is successfully raised, limited access to appropriate healthcare services can hinder individuals from acting on this information.

These findings suggest that health communication efforts cannot be effective in isolation. Increasing public awareness must be accompanied by improvements within the healthcare system itself. This includes enhancing medical education and ensuring that healthcare professionals are adequately equipped to recognize and treat the condition. As previous research indicates, expanding medical knowledge is closely tied to broader structural factors such as research funding and institutional priorities (Hallström, 2024, p. 21; Harder et al., 2024, p. 896). Without corresponding structural change, health communication aimed at raising awareness risks reinforcing rather than resolving the challenges faced by individuals affected by a silent disease.

# 5 Conclusion

*"It's not talked about enough. It's not covered enough. It's not studied enough. It's just not enough" (Osanna, FG 3)*.

This thesis explored how physically and socially invisible conditions, conceptualized here as "silent diseases", are produced, negotiated, and communicated through health communication. Using endometriosis as a case study, it examined how individuals navigate and evaluate health communication sources and how media and communication shape awareness, recognition, and understanding of the condition. Central to this thesis were the voices and lived experiences of individuals with endometriosis, treated as valuable epistemic resources. In doing so, the study builds on Harding's (2008) feminist standpoint theory by emphasizing the importance of including marginalized voices in knowledge production. A social constructivist perspective further enabled an examination of how health and illness are socially produced and negotiated. Drawing on Foucault's conceptualization of the body and Lupton's (2012) discussions of gendered health and the historical marginalization of women's health issues, this thesis explored how endometriosis has been silenced and socially minimized. Three research questions guided the analysis.

**The first research question examined how individuals with (or with suspected) endometriosis navigate and evaluate sources of information and support throughout their health journey.** Participants primarily discovered endometriosis through online searches or social networks rather than through healthcare professionals. They relied on a broad range of online and offline sources, including websites, scientific studies, AI tools, social media, online communities, and interpersonal relationships. While these sources often provided validation and support, they could also become emotionally overwhelming, creating a tension between engagement and withdrawal. The findings suggest that individuals with endometriosis must navigate a fragmented information landscape shaped by insufficient institutional health communication. Formal sources were frequently perceived as limited, outdated, or overly generalized, forcing affected individuals to assemble knowledge independently from scattered informal sources. In this context, participatory, bottom-up forms of communication, particularly through social media, played a central role because they "stretch beyond the local realm" (Lindgren, 2022, p. 108), enabling the circulation of experiential knowledge, validation, and emotional support across broader networks. Testimonials and lived experience were often regarded as the most trustworthy sources of information. This reliance on participatory communication reflects broader structural failures within healthcare and institutional

communication, which contributed to participants' experiences of self-doubt, dismissal, and internalized stigma.

**The second research question explored how individuals with (or with suspected) endometriosis perceive and reflect on the role of media and communication in shaping awareness, recognition, and understanding of the condition.** Participants' accounts revealed a recurring dynamic that this thesis conceptualizes as the *Vicious Circle of Silent Suffering*. When individuals attempted to make their condition visible by speaking about it, they were frequently met with disbelief, misunderstanding, or stigmatization. These external reactions often became internalized, contributing to self-doubt and discouraging individuals from seeking medical care, thereby reinforcing further invisibility. The invisibility leads others to underestimate the condition, which is reflected in the "beautiful is healthy" stereotype (Hallström, 2024, p. 15). Participants described experiences of dismissal in both healthcare settings and everyday social interactions. While many did not want to be reduced to their condition, they nevertheless expressed a strong desire for public understanding, legitimacy, and compassion. Comparisons with conditions such as cancer or diabetes highlighted perceived inequalities in recognition, resources, and institutional support. Participants agreed that health communication is essential for increasing the visibility of endometriosis, which may, in turn, help weaken or interrupt the *Vicious Circle of Silent Suffering*.

Participants further provided valuable insights into how health communication regarding endometriosis could be designed more effectively. They emphasized that communication should target both affected individuals and the broader social and institutional environments surrounding them, including schools, parents, teachers, and healthcare professionals. This aligns with socio-ecological approaches to health promotion, which emphasize that communication should facilitate change across interpersonal, community, and societal levels (Lewis and Lewis, 2015, pp. 7–8).

Three key themes emerged regarding communication content. First, participants emphasized the need to communicate the complexity, unpredictability, and diverse symptomatology of endometriosis more accurately. Second, participants highlighted tensions surrounding representations of severe suffering. While some found such portrayals validating and effective in raising awareness, others found them intimidating and reported that they reinforced feelings of self-doubt. Third, participants called for more nuanced communication that includes alternative treatment options, post-diagnosis support, and culturally sensitive representations.

These findings suggest that effective health communication must balance visibility with responsible representation.

Regarding channels and formats, participants advocated for a strategic combination of communication forms. While social media was seen as effective for reaching individuals already engaged with the topic, participants believed that mass-mediated and physical communication formats were necessary to reach unaware publics. Suggestions included posters in schools and on public transport, awareness messages on everyday products as a form of "philanthropic marketing" linking products to a broader social cause (Thorne McAlister and Ferrell, 2002), and representations in popular culture formats resembling entertainment-education strategies (Lewis and Lewis, 2015, p. 154). Participants emphasized the importance of embedding health communication into everyday environments, both physical and mediated, to make information more accessible.

Overall, participants argued for a combination of participatory, bottom-up communication and institutional, top-down initiatives. Testimonials and personal advocacy were viewed as powerful tools for increasing visibility and reducing stigma. However, participants also stressed that awareness should not depend solely on affected individuals. Institutional actors, particularly official health authorities supported by governmental structures, were considered essential due to their reach, legitimacy, and influence. As Elvira (FG 3) summarized, endometriosis should be communicated "on every platform possible".

**The third research question asked what the case of endometriosis reveals about the role of health communication in shaping the visibility of "silent diseases".** The findings suggest that insufficient health communication creates what this thesis conceptualizes as a *Triple Burden* for affected individuals. They are forced to become (1) self-educators, navigating fragmented landscapes of information and support; (2) self-advocates, consistently asserting the legitimacy of their condition to others and themselves; and (3) participatory communicators, compensating for insufficient formal health communication. While participatory communication can be empowering, the findings also demonstrate a broader structural failure: when formal health communication is lacking, participatory efforts shift from being supplementary and optional to becoming necessary.

To address these burdens, the findings further indicate that effective communication surrounding silent diseases requires both bottom-up and top-down approaches, with the most effective scenario being their integration. Bottom-up communication, particularly through

testimonials and lived experience, can provide visibility, emotional support, and nuanced representation. However, it often primarily reaches audiences already familiar with the condition and may also become emotionally exhausting for those involved. Top-down communication is therefore necessary to achieve broader public reach, legitimacy, and structural support. Participants particularly emphasized the responsibility of official health authorities and governmental institutions to lead awareness efforts and improve education within healthcare systems. At the same time, top-down communication must remain grounded in lived experience to avoid oversimplification and harmful misrepresentation, which may discourage individuals from seeking care. Campaigns such as *#1in10* illustrate how this integration can be achieved (Stanek et al., 2023). Overall, the findings suggest that communication surrounding silent diseases is most effective when participatory knowledge and institutional legitimacy reinforce one another.

Finally, this thesis suggests that health communication efforts cannot be effective in isolation but must be accompanied by broader structural improvements within healthcare systems to ensure adequate recognition, diagnosis, and treatment of the condition. Such change is closely tied to factors including research funding, medical education, and political priorities (Hallström, 2024; Harder et al., 2024). Without these structural developments, health communication aimed at raising awareness risks reinforcing rather than resolving the challenges faced by individuals affected by silent diseases, as greater awareness may raise expectations for recognition and care that healthcare systems are still insufficiently prepared to meet.

This thesis faces several limitations. First, the study relied exclusively on qualitative focus group data and therefore lacks methodological triangulation. Second, as the study primarily included individuals identifying as female, experiences across more diverse gender identities remain underexplored. Third, because the sample consisted primarily of European participants, the transferability of findings across different cultural and healthcare contexts is limited.

Despite these limitations, this thesis makes several important contributions. Empirically, it amplifies the voices and lived experiences of individuals with endometriosis, addressing longstanding critiques that experiences and perspectives of people assigned female at birth have historically been marginalized within research (Denny, 2004; Seear, 2014). Conceptually, the thesis reconceptualizes “silent diseases” through a social constructivist and health communication perspective. Rather than understanding silence as the absence of symptoms, as often found in medical literature (e.g., Mafi Golchin et al., 2016), this thesis conceptualizes silence as a condition of physical and social invisibility, in which suffering remains difficult to

recognize, communicate, and legitimize. In this context, it develops the concepts of the *Vicious Circle of Silent Suffering* and the *Triple Burden* to explain how communicative invisibility shapes the experiences of affected individuals. In doing so, the thesis contributes to broader discussions surrounding the social construction of health and illness and demonstrates how gendered health issues are systematically minimized and silenced.

The thesis also contributes to health communication research by examining both the consequences of insufficient communication and the potential of integrated communication strategies in the context of silent diseases. It argues that communication surrounding silent diseases requires the combination and integration of bottom-up and top-down health communication approaches (Lewis and Lewis, 2015), bringing together institutional reach and legitimacy with participatory knowledge grounded in lived experience. In this sense, the study also extends existing discussions of participatory health communication by demonstrating that, in contexts of institutional silence, participatory communication shifts from supplementary to necessary. The findings further underline the importance of political involvement in awareness efforts. The Australian case demonstrates how governmental engagement can contribute to increased research funding, public awareness, and structural reform through initiatives such as the National Action Plan for Endometriosis (Armour et al., 2022; Australian Government Department of Health, 2024).

Although the study primarily reflects European perspectives, its findings may also hold relevance for other contexts in which gendered illnesses remain stigmatized, underrecognized, and socially silenced. Future research could further examine silent diseases across different cultural and national contexts and explore how communication strategies may vary accordingly. Such approaches would be particularly valuable for further developing the concepts introduced in this thesis. Ultimately, this thesis hopes to contribute to greater recognition, understanding, and compassion for individuals living with socially silenced conditions such as endometriosis.

## References


Abdo, A.M.E.-S. (2023) "Health Awareness Campaigns and Their Role in Promoting Awareness of Rare Diseases," *Journal of Design Sciences and Applied Arts*, 4(2), pp. 70–83. Available at: https://doi.org/10.21608/jdsaa.2023.173961.1236.

Anker, A.E. *et al.* (2016) "Measuring the Effectiveness of Mass-Mediated Health Campaigns Through Meta-Analysis," *Journal of Health Communication*, 21(4), pp. 439–456. Available at: https://doi.org/10.1080/10810730.2015.1095820.

Arena, A. *et al.* (2022) "The social media effect: the impact of fake news on women affected by endometriosis. A prospective observational study," *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 274, pp. 101–105. Available at: https://doi.org/10.1016/j.ejogrb.2022.05.020.

Armour, M. *et al.* (2022) "Lessons from implementing the Australian National Action Plan for Endometriosis," *Reproduction & Fertility*, 3(3), pp. C29–C39. Available at: https://doi.org/10.1530/RAF-22-0003.

Australian Government Department of Health (2018) "National Action Plan for Endometriosis." Available at: https://www.health.gov.au/sites/default/files/national-action-plan-for-endometriosis.pdf.

Australian Government Department of Health (2024) "Endometriosis Progress Report 2024 Update." Available at: https://www.health.gov.au/sites/default/files/2024-03/endometriosis-progress-report-2024_1.pdf.

Ballard, K., Lowton, K. and Wright, J. (2006) "What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis," *Fertility and Sterility*, 86(5), pp. 1296–1301. Available at: https://doi.org/10.1016/j.fertnstert.2006.04.054.

Barth (2008) "Michel Foucault: Wahnsinn und Gesellschaft," *Einhundert Meisterwerke der Psychotherapie* [Preprint]. Available at: https://doi.org/10.1007/978-3-211-69499-2_27.

Batt, R. (2011) *A History of Endometriosis*. Springer Science & Business Media.

Bloski, T. and Pierson, R. (2008) "Endometriosis and Chronic Pelvic Pain: Unraveling the Mystery Behind this Complex Condition," *Nursing for Women's Health*, 12(5), pp. 382–395. Available at: https://doi.org/10.1111/j.1751-486X.2008.00362.x.

Bologna, F. *et al.* (2024) "Endometriosis Online Communities: A Quantitative Analysis." medRxiv, p. 2024.02.27.24303445. Available at: https://doi.org/10.1101/2024.02.27.24303445.

Brann, M. (2024) "Essential instructional communication concepts for effective health campaigns.," *Communication Education*, 73(4), pp. 427–435. Available at: https://doi.org/10.1080/03634523.2024.2383174.

Brezinka, C. (2021) "Was ändert sich bei Beschwerden und Klagen zu Gynäkologie?," *Journal für Gynäkologische Endokrinologie/Österreich*, 31(4), pp. 136–138. Available at: https://doi.org/10.1007/s41974-021-00204-9.

Cancarevic, I., Plichtová, L. and Malik, B.H. (2021) "Healthcare Systems Around the World," in H. Tohid and H. Maibach (eds.) *International Medical Graduates in the United States: A Complete Guide to Challenges and Solutions*. Cham: Springer International Publishing, pp. 45–79. Available at: https://doi.org/10.1007/978-3-030-62249-7_3.

Charmaz, K. (2006) *Constructing grounded theory: a practical guide through qualitative analysis*. London; Thousand Oaks; New Delhi: Sage.

Criado Perez, C. (2019) *Invisible women: data bias in a world designed for men*. New York: Abrams Press.

Culley, L. *et al.* (2013) "The social and psychological impact of endometriosis on women's lives: a critical narrative review," *Human Reproduction Update*, 19(6), pp. 625–639. Available at: https://doi.org/10.1093/humupd/dmt027.

Denny, E. (2004) "Women's experience of endometriosis," *Journal of Advanced Nursing*, 46(6), pp. 641–648. Available at: https://doi.org/10.1111/j.1365-2648.2004.03055.x.

Eder, C. and Roomaney, R. (2025) "Being an outsider: transgender and non-binary experiences within online endometriosis communities," *South African Journal of Psychology* [Preprint]. Available at: https://doi.org/doi.org/10.1177/008124632513574.

*Educate – Endo What?* (no date). Available at: https://endowhat.com/educate/ (Accessed: March 19, 2025).

Eitze, S. and Reinhardt, A. (2025) "Keep Period Pain a Secret? Expanding the Theory of Planned Behavior With Endometriosis Knowledge and Menstrual Stigma to Explain Women's Intentions to Talk About Menstrual Discomfort," *Health Psychology*, 44(11). Available at: https://doi.org/https://doi.org/10.1037/hea0001502.

Ellis, K., Munro, D. and Clarke, J. (2022) "Endometriosis Is Undervalued: A Call to Action," *Frontiers in Global Women's Health*, 3. Available at: https://doi.org/10.3389/fgwh.2022.902371.

Ellis, K. and Wood, R. (2026) "Endometriosis and the Hallmarks of Cancer," *Reproductive Sciences*, 33(1), pp. 32–46. Available at: https://doi.org/10.1007/s43032-025-02024-0.

Flyvbjerg, B. (2001) *Making Social Science Matter: Why social inquiry fails and how it can succeed again*. New York: Cambridge University Press.

Fuster, V. and Moreno, P.R. (2005) "Atherothrombosis as a systemic, often silent, disease," *Nature Clinical Practice Cardiovascular Medicine*, 2(9), pp. 431–431. Available at: https://doi.org/10.1038/ncpcardio0310.

Gao, X. *et al.* (2006) "Economic burden of endometriosis," *Fertility and Sterility*, 86(6), pp. 1561–1572. Available at: https://doi.org/10.1016/j.fertnstert.2006.06.015.

Ghiasi, M., Kulkarni, M.T. and Missmer, S.A. (2020) "Is Endometriosis More Common and More Severe Than It Was 30 Years Ago?," *Journal of Minimally Invasive Gynecology*, 27(2), pp. 452–461. Available at: https://doi.org/10.1016/j.jmig.2019.11.018.

Goffman, E. (1986) *Stigma: notes on the management of spoiled identity*. 1. Touchstone ed. New York: Simon & Schuster.

Grundström, H. *et al.* (2020) "'A protracted struggle' – A qualitative blog study of endometriosis healthcare experiences in Sweden," *Australian Journal of Advanced Nursing*, 37(4). Available at: https://doi.org/10.37464/2020.374.75.

Guidone, H.C. (2020) "The Womb Wanders Not: Enhancing Endometriosis Education in a Culture of Menstrual Misinformation," in C. Bobel et al. (eds.) *The Palgrave Handbook of Critical Menstruation Studies*. Singapore: Springer Singapore, pp. 269–286. Available at: https://doi.org/10.1007/978-981-15-0614-7_22.

Gupta, J. *et al.* (2018) "How do adolescent girls and boys perceive symptoms suggestive of endometriosis among their peers? Findings from focus group discussions in New York

City," *BMJ Open*, 8(6), pp. 1–11. Available at: https://doi.org/10.1136/bmjopen-2017-020657.

Hallström, I. (2024) "Endo Episteme: Epistemic Injustice and the Misrecognition of Endometriosis," *Feminist Philosophy Quarterly*, 10(4). Available at: https://ojs.lib.uwo.ca/index.php/fpq/article/view/16491 (Accessed: December 4, 2025).

Hansen, A. and Machin, D. (2019) *Media and Communication Research Methods*. 2nd ed. London: Macmillan Education UK. Available at: https://doi.org/10.1007/978-1-137-27225-6.

Harder, C. *et al.* (2024) "Assessing the true prevalence of endometriosis: A narrative review of literature data," *International Journal of Gynecology & Obstetrics*, 167(3), pp. 883–900. Available at: https://doi.org/10.1002/ijgo.15756.

Harding, S. (2008) *Sciences from below: Feminism, Postcolonialities, and Modernities*. Durham & London: Duke University Press.

van den Haspel, K. *et al.* (2022) "The role of social media in management of individuals with endometriosis: A cross-sectional study," *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 62(5), pp. 701–706. Available at: https://doi.org/10.1111/ajo.13524.

Holowka, E.M. (2022) "Mediating Pain: Navigating Endometriosis on Social Media," *Frontiers in Pain Research*, 3. Available at: https://doi.org/10.3389/fpain.2022.889990.

Hudson, N. (2022) "The missed disease? Endometriosis as an example of 'undone science,'" *Reproductive Biomedicine & Society Online*, 14, pp. 20–27. Available at: https://doi.org/10.1016/j.rbms.2021.07.003.

Hurst, A. (2023) "Introduction to Qualitative Research Methods: A Helpful Guide for Undergraduates and Graduate Students in the Social Sciences."

Jabr, F.I. and Mani, V. (2014) "An unusual cause of abdominal pain in a male patient: Endometriosis," *Avicenna Journal of Medicine*, 04(04), pp. 99–101. Available at: https://doi.org/10.4103/2231-0770.140660.

Jensen, K.B. (2012) *The handbook of media and communication research: qualitative and quantitative methodologies*. 2nd ed. New York: Routledge.

Jones, C.E. (2015) "Wandering Wombs and 'Female Troubles': The Hysterical Origins, Symptoms, and Treatments of Endometriosis," *Women's Studies*, 44(8), pp. 1083–1113. Available at: https://doi.org/10.1080/00497878.2015.1078212.

Kadhim, B.J. and Abbas, R.H. (2019) "Causes of Infertility in Women," *World Journal of Pharmaceutical Research*, 8(5), pp. 453–465. Available at: https://doi.org/10.20959/wjpr20195-14666.

Kasturia, S. (2023) "Role of Mass Media in Achieving Sustainable Healthcare," *International Journal of Humanities and Social Science Invention*, 12(9), pp. 110–115.

Kees, J. *et al.* (2010) "Understanding how Graphic Pictorial Warnings Work on Cigarette Packaging," *Journal of Public Policy & Marketing*, 29(2), pp. 265–276. Available at: https://doi.org/10.1509/jppm.29.2.265.

König, A. and Meier zu Biesen, C. (2025) "'Activism Was a Survival Strategy': Chronic Illness and the Power of Endometriosis Activism as Work," *Anthropology of Work Review*, 46(1). Available at: https://doi.org/10.1111/awr.70005.

Krebs, E. and Schoenbauer, K.V. (2019) “Hysterics and Heresy: Using Dialogism to Explore the Problematics of Endometriosis Diagnosis,” *Health Communication*, 35(8), pp. 1013–1022. Available at: https://doi.org/10.1080/10410236.2019.1606136.

Kuckartz, U. (2014) *Qualitative Text Analysis: A Guide to Methods, Practice and Using Software*. Los Angeles: SAGE Publications Ltd. Available at: https://doi.org/10.4135/9781446288719.

Kvinnohistoriska (2024) *Ina Hallström: How recognition shapes lives*. Available at: https://www.youtube.com/watch?v=SjCYvazl5LA (Accessed: May 1, 2026).

Kvinnohistoriska Museum (2024) *Understanding Endometriosis*, *Kvinnohistoriska*. Available at: https://www.kvinnohistoriska.se/pain-unseen/endo (Accessed: May 5, 2026).

Lambert, S.D. and Loiselle, C.G. (2007) “Health Information—Seeking Behavior,” *Qualitative Health Research*, 17(8), pp. 1006–1019. Available at: https://doi.org/10.1177/1049732307305199.

Lamceva, J., Uljanovs, R. and Strumfa, I. (2023) “The Main Theories on the Pathogenesis of Endometriosis,” *International Journal of Molecular Sciences*, 24(5), p. 4254. Available at: https://doi.org/10.3390/ijms24054254.

LeBlanc, S. (2025) “They Don’t Look Sick - Popular Culture and Women’s Health,” in C.S. Beck (ed.) *The Routledge Handbook of Health Communication and Popular Culture*. New York & London: Routledge (Routledge Handbooks of Communication Studies).

Lewis, B. and Lewis, J. (2015) *Health communication: a media and cultural studies approach*. London ; New York, NY: Palgrave Macmillan Publishers.

Lindgren, S. (2022) *Digital media & society*. 2nd edition. London ; Thousand Oaks, California: SAGE Publications Ltd.

Lupton, D. (2012) *Medicine as Culture: Illness, Disease and the Body*. London: SAGE Publications Ltd. Available at: https://doi.org/10.4135/9781446254530.

Lupton, D. (2017) *Digital Health: Critical and Cross-Disciplinary Perspectives*. London: Routledge. Available at: https://doi.org/10.4324/9781315648835.

Ma, L., Wang, Yijing and Wang, Yuan (2026) “Bounded Supportive Companionship: How Chinese Young Adults Seek Emotional Support from Generative AI Chatbots,” *Health Communication*, 0(0), pp. 1–10. Available at: https://doi.org/10.1080/10410236.2026.2660147.

Mafi Golchin, M. *et al.* (2016) “Osteoporosis: A Silent Disease with Complex Genetic Contribution,” *Journal of Genetics and Genomics*, 43(2), pp. 49–61. Available at: https://doi.org/10.1016/j.jgg.2015.12.001.

Matías-González, Y. *et al.* (2021) “‘Es que tú eres una changa’: stigma experiences among Latina women living with endometriosis,” *Journal of Psychosomatic Obstetrics & Gynecology*, 42(1), pp. 67–74. Available at: https://doi.org/10.1080/0167482X.2020.1822807.

Mayat, H., Rivera, M. and Lane, S.D. (2022) “Gender and Health,” in S. Scrimshaw et al. (eds.) *The SAGE Handbook of Social Studies in Health and Medicine*. 1 Oliver’s Yard, 55 City Road London EC1Y 1SP: SAGE Publications Ltd, pp. 249–274. Available at: https://doi.org/10.4135/9781529714357.

Melander, I. (2019) “Multimodal Illness Narratives on Instagram. Sharing the Experience of Endometriosis,” *DIEGESIS*, 8(2). Available at: https://www.diegesis.uni-wuppertal.de/index.php/diegesis/article/view/358 (Accessed: November 24, 2025).

Mettler, L. and Schmutzler, A. (2007) “Endometriose,” in K. Diedrich et al. (eds.) *Gynäkologie und Geburtshilfe*. Berlin, Heidelberg: Springer, pp. 299–311. Available at: https://doi.org/10.1007/978-3-540-32868-1_12.

Missmer, S.A. *et al.* (2021) “Impact of Endometriosis on Life-Course Potential: A Narrative Review,” *International Journal of General Medicine*, 14, pp. 9–25. Available at: https://doi.org/10.2147/IJGM.S261139.

Missmer, S.A. *et al.* (2022) “Impact of endometriosis on women’s life decisions and goal attainment: a cross-sectional survey of members of an online patient community,” *BMJ Open*, 12(4), pp. 1–10. Available at: https://doi.org/10.1136/bmjopen-2021-052765.

Morgan, D.L. (1997) *Focus Groups as Qualitative Research*. Thousand Oaks, CA: SAGE Publications, Inc. Available at: https://doi.org/10.4135/9781412984287.

Neugebauer, T. *et al.* (2025) “Endometriosis– ‘Either way a tragedy’? A qualitative social media analysis of endometriosis perceptions in Germany,” *BMC Women’s Health*, 25, pp. 1–9. Available at: https://doi.org/10.1186/s12905-025-03865-2.

Nezhat, Camran, Nezhat, F. and Nezhat, Ceana (2012) “Endometriosis: ancient disease, ancient treatments,” *Fertility and Sterility*, 98(6, Supplement), pp. S1–S62. Available at: https://doi.org/10.1016/j.fertnstert.2012.08.001.

Nnoaham, K.E. *et al.* (2019) “Reprint of: Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries,” *Fertility and Sterility*, 112(4), pp. e137–e152. Available at: https://doi.org/10.1016/j.fertnstert.2019.08.082.

Polo-Kantola, P. (2008) “Dealing with Menopausal Sleep Disturbances,” *Sleep Medicine Clinics*, 3(1), pp. 121–131. Available at: https://doi.org/10.1016/j.jsmc.2007.10.006.

Pryor, R. *et al.* (2025) “No Excuse for Abuse: Evaluation of a Public Health Campaign To Increase Awareness and Change Attitudes Toward Non-Physical Domestic Violence: Domestic Violence Awareness Campaign,” *Journal of Family Violence* [Preprint]. Available at: https://doi.org/10.1007/s10896-025-00957-3.

Rei, C., Williams, T. and Feloney, M. (2018) “Endometriosis in a Man as a Rare Source of Abdominal Pain: A Case Report and Review of the Literature,” *Case Reports in Obstetrics and Gynecology*, 2018(1), p. 2083121. Available at: https://doi.org/10.1155/2018/2083121.

Rice, R.E. and Atkin, C.K. (2013) “Theory and Principles of Public Communication Campaigns,” in R.E. Rice and C.K. Atkin (eds.) *Public Communication Campaigns*. 4th ed. Los Angeles London New Delhi Singapore Washington DC Melbourne: SAGE Publications, pp. 3–19.

Robvais, R.M. (2020) “We are No Longer Invisible,” *POROI*, 15(1), pp. 1–18. Available at: https://doi.org/10.13008/2151-2957.1296.

Salamon, M. (2023) *Invisible illness: More than meets the eye*, *Harvard Health*. Available at: https://www.health.harvard.edu/diseases-and-conditions/invisible-illness-more-than-meets-the-eye (Accessed: May 5, 2026).

Sassatelli, R. (2012) “Body Politics,” in E. Amenta, K. Nash, and A. Scott (eds.) *The Wiley-Blackwell Companion to Political Sociology*. John Wiley & Sons, Ltd, pp. 347–359. Available at: https://doi.org/10.1002/9781444355093.ch31.

Sbaffi, L. and King, K. (2020) “Living with Endometriosis: The Role of the Internet in Supporting the Diagnosis and Treatment Process,” *Journal of Consumer Health on the*

*Internet*, 24(4), pp. 370–390. Available at: https://doi.org/10.1080/15398285.2020.1816803.

Seear, K. (2014) *The makings of a modern epidemic: Endometriosis, gender and politics*. Ashgate Publishing Ltd.

Senyel, D., Boyd, J.H. and Graham, M. (2025) "Informational support for women with endometriosis: a scoping review," *BMC Women's Health*, 25(1), pp. 1–11. Available at: https://doi.org/10.1186/s12905-025-03581-x.

Senyel, D., Boyd, J.H. and Graham, M. (2026) "Information-Seeking Behaviours of CALD Women with Endometriosis in Australia: A Qualitative Study," *International Journal of Environmental Research and Public Health*, 23(1), pp. 1–20. Available at: https://doi.org/10.3390/ijerph23010134.

Seo, H. *et al.* (2025) "Social media activism and women's health: Endometriosis awareness and support," *DIGITAL HEALTH*, 11, pp. 1–12. Available at: https://doi.org/10.1177/20552076251314905.

Shadbolt, N.A., Parker, M.A. and Orthia, L.A. (2013) "Communicating endometriosis with young women to decrease diagnosis time," *Health Promotion Journal of Australia*, 24(2), pp. 151–154. Available at: https://doi.org/10.1071/HE12915.

Shah, D.K. *et al.* (2010) "Public perceptions of endometriosis: perspectives from both genders," *Acta Obstetricia et Gynecologica Scandinavica*, 89(5), pp. 646–650. Available at: https://doi.org/10.3109/00016341003657900.

Shiplo, S.N. *et al.* (2025) "Endometriosis Influencers on Instagram: Who Are They and What Are They Posting?," *Journal of Minimally Invasive Gynecology*, 32(8), pp. 693–700. Available at: https://doi.org/10.1016/j.jmig.2025.01.018.

Simoens, S. *et al.* (2012) "The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres," *Human Reproduction*, 27(5), pp. 1292–1299. Available at: https://doi.org/10.1093/humrep/des073.

Simone, L. (2025) "Re-evaluating Endometriosis Management in Adolescents: Clinical Challenges and Emerging Strategies," *Journal of Women Health*, 1(2).

Sims, O.T. *et al.* (2021) "Stigma and Endometriosis: A Brief Overview and Recommendations to Improve Psychosocial Well-Being and Diagnostic Delay," *International Journal of Environmental Research and Public Health*, 18(15), pp. 1–12. Available at: https://doi.org/10.3390/ijerph18158210.

Socialstyrelsen (ed.) (2018) *Nationella riktlinjer för vård vid endometrios: stöd för styrning och ledning*. Stockholm: Socialstyrelsen.

Stanek, D.B. *et al.* (2023) "Not 'just a bad period'— The impact of a co-created endometriosis social media health campaign: a mixed methods study," *Frontiers in Communication*, 8. Available at: https://doi.org/10.3389/fcomm.2023.1154297.

Statista Research Department (2026) *Social network usage by brand in Sweden 2025*, *Statista*. Available at: https://www.statista.com/forecasts/1348052/social-network-usage-by-brand-in-sweden/ (Accessed: April 26, 2026).

Strange, J.-M. (2000) "Menstrual fictions: languages of medicine and menstruation, c. 1850–1930," *Women's History Review*, 9(3), pp. 607–628. Available at: https://doi.org/10.1080/09612020000200260.

SVT Nyheter (2024) *Första endometrioskliniken i Sverige öppnar i Stockholm*, *SVT Nyheter*. Stockholm. Available at: https://www.svt.se/nyheter/lokalt/stockholm/forsta-endometrioskliniken-i-sverige-oppnar-i-stockholm (Accessed: January 28, 2026).

Taylor, H.S., Kotlyar, A.M. and Flores, V.A. (2021) "Endometriosis is a chronic systemic disease: clinical challenges and novel innovations," *The Lancet*, 397(10276), pp. 839–852. Available at: https://doi.org/10.1016/S0140-6736(21)00389-5.

Thorne McAlister, D. and Ferrell, L. (2002) "The role of strategic philanthropy in marketing strategy," *European Journal of Marketing*, 36(5/6), pp. 689–705. Available at: https://doi.org/10.1108/03090560210422952.

Towne, J. *et al.* (2021) "Health Information in the Era of Social Media: An Analysis of the Nature and Accuracy of Posts Made by Public Facebook Pages for Patients with Endometriosis," *Journal of Minimally Invasive Gynecology*, 28(9), pp. 1637–1642. Available at: https://doi.org/10.1016/j.jmig.2021.02.005.

Tragantzopoulou, P. (2024) "Endometriosis and stigmatization: A literature review," *Journal of Endometriosis and Pelvic Pain Disorders*, 16(2), pp. 117–122. Available at: https://doi.org/10.1177/22840265241248488.

Turner, B.S. (1997) "Foreword: From governmentality to risk. Some reflections on Foucault's contribution to medical sociology," in A. Petersen and R. Bunton (eds.) *Foucault, Health and Medicine*. London: Routledge.

Vicari, S. (2021) *Digital Media and Participatory Cultures of Health and Illness*. New York: Routledge. Available at: https://doi.org/10.4324/9780429469145.

Wakefield, M.A., Loken, B. and Hornik, R.C. (2010) "Use of mass media campaigns to change health behaviour," *The Lancet*, 376(9748), pp. 1261–1271. Available at: https://doi.org/10.1016/S0140-6736(10)60809-4.

Werder, K.P. (2020) "Public Sector Communication and Strategic Communication Campaigns," in M.J. Canel and V. Luoma-aho (eds.) *The Handbook of Public Sector Communication*. Hoboken, NJ: John Wiley & Sons, Inc (Handbooks in Communication and Media).

Whelan, E. (2007) "'No one agrees except for those of us who have it': endometriosis patients as an epistemological community," *Sociology of Health & Illness*, 29(7), pp. 957–982. Available at: https://doi.org/10.1111/j.1467-9566.2007.01024.x.

World Health Organization (2025) *Endometriosis*. Available at: https://www.who.int/news-room/fact-sheets/detail/endometriosis (Accessed: November 26, 2025).

Wright, K.B., Sparks, L. and O'Hair, H.D. (2012) *Health Communication in the 21st Century*. John Wiley & Sons.

Zhao, X. (2020) "Health communication campaigns: A brief introduction and call for dialogue," *International Journal of Nursing Sciences*, 7, pp. S11–S15. Available at: https://doi.org/10.1016/j.ijnss.2020.04.009.

Zondervan, K.T., Becker, C.M. and Missmer, S.A. (2020) "Endometriosis," *New England Journal of Medicine*, 382(13), pp. 1244–1256. Available at: https://doi.org/10.1056/NEJMra1810764.

**Additional References for Stimulus Material**


Brown, N. (2024) “Heartbreaking video Australia needs to see,” *news.com.au*, 29 February. Available at: https://www.news.com.au/lifestyle/health/health-problems/heartbreaking-video-australia-needs-to-see/news-story/87355dcb1f78733c93166ddf5cc83b25 (Accessed: December 1, 2025).

Endometriosis Australia (2024) *Endometriosis Australia Life on Hold*. Available at: https://www.youtube.com/watch?v=UV0Batgex_4 (Accessed: May 14, 2026).

Kvinnohistoriska Museum (2024) *Pain Unseen – digital utställning om endometrios*, *Kvinnohistoriska*. Available at: https://www.kvinnohistoriska.se/pain-unseen (Accessed: January 29, 2026).

Socialstyrelsen (2018) *Mycket mensvärk är inte okej*, *Socialstyrelsen*. Available at: https://www.socialstyrelsen.se/mycketmensvark/ (Accessed: January 29, 2026).

*This Is Endometriosis* [Short Film] (2024). Available at: https://www.thisisendo.com/watch-this-is-endometriosis.

# Appendices

**Appendix A.** *Swedish Endometriosis Support Groups on Facebook*

| Group Name | Link |
|---|---|
| “Endometrios” | https://www.facebook.com/groups/endometriossverige/ |
| “Leva med Endometrios – Öppna gruppen” | https://www.facebook.com/groups/2113348072227789/ |
| “Leka endometrios naturligt” | https://www.facebook.com/groups/693276357409999/ |
| “Leva med endometrios Sverige” | https://www.facebook.com/groups/482048418489279/ |
| “Endometriosföreningen Sverige Öppen grupp” | https://www.facebook.com/groups/23093072995/ |

## **Appendix B.** *Focus Group Discussion Guide*

### Focus Group – Discussion Guide

**Intro:**

**I will start the recording now.**
**Thank you for participating in this group discussion. You have all signed the consent form and confidentiality agreement. So, we will treat everything in this room confidentially.**
**A reminder: Some of the experiences that we cover today can be personal and emotional. Please feel free to share as little or as much as you want and skip any question you don't feel comfortable with. And it is, of course, at all times okay to ask for the recording to be stopped and to leave the discussion.**

I want to start by saying: I also have a background of endometriosis. I was diagnosed in 2022. But I am by no means an expert on endometriosis; I am still learning every day.
That is the reason why I am doing this research in the first place.
Today, **I** am acting as a moderator. **You** will be discussing your **individual** experiences with endometriosis – how you found out about endometriosis, how you seek information, the role of media in your health journey, and different initiatives to create awareness.
The most important point: I am here to learn from you. I'm interested in your personal experiences and perspectives. And since those are individual, there are no right or wrong answers. Every story is valuable.

Before we start, I will quickly introduce **a few "ground rules":**

1. Try to hear from everyone in the group. And talk to each other – not just to me.
   Basically, the aim is to have a conversation, and I will give you some prompts along the way.
2. It is completely okay to use your phones to show examples or look something up, if you feel like that's helpful.
3. We will talk for about 1,5-2 hours, and we can have a short break in the middle.
4. Please feel free to always get up and move around if you need to, and grab more fika if you like.

**Any questions?**

**Ice Breaker question:**

I would like to start with an introduction round:

**Can each of you tell us your name and pronouns, age, profession, and something that you like to do for fun?**

**1. Discussion-Starter question:**

Now that we've gotten to know each other a little better, let's start talking about the topic we are here for.

**Can each of you tell us a little about your endometriosis journey?**

- When did you start suspecting something was wrong?
- When did you first hear about endometriosis?
- How did you find out that you might have it?
- Why do you think diagnosis took as long as it did?

**2.** When you were looking for answers, **where did you look for information?**

- Is it easy or difficult to find information about endometriosis?
- What did you struggle with?
- **What sources did you trust**?

- What kind of information were you looking for?
- **Where do you turn for support?**
- Did you talk to anyone (doctors, friends, communities)?

3. **What role has media played in your endometriosis health journey?**
    - What kind of media channels have you used?
    - **Has anyone tried consulting an AI Chatbot? What does everyone think about that?**

***BREAK (5-10 mins)***

4. *Introduce examples of endometriosis awareness initiatives:* ***I have sent you*** *….*
    - *Digital exhibition (Pain Unseen) by the Stockholm Museum of Women's History*
    - *A Swedish awareness campaign targeted at teenagers who menstruate (Severe period pain is not okay!)*
    - *Two Australian Campaigns (About Bloody Time (News agency) & Take Your Life Off Hold (National TV))*
    - *The trailer to THIS IS ENDOMETRIOSIS, a short film that won at the British Academy Film Awards*

    **What do you think about these initiatives to spread awareness of endometriosis?**
    - Do they represent the condition accurately?
    - Would they have helped you earlier?
    - Who do you think these campaigns are for?

5. **If you could design the ideal information resources about endometriosis, what would they look like?** I have some questions for you to help you get started (SHOW THEM THE PROMPTS BELOW)
    - Who would you like to reach?
    - What topics should be covered?
    - How would you distribute the information?
        - What channel(s) would you use?
        - Offline/Online?
        - Which type of meedia?
    - Who should be the sender of the information?

    Since you have gone through this process of finding out about endometriosis:
    **How would you suggest reaching people who might have endo but don't know about the disease yet?**

**<u>End of discussion:</u>**

Now that we have covered many different topics, I would like to know one more thing.

**What advice would you give to people who are at the very beginning of their endometriosis journey right now?**

**Would anyone like to add anything?**

**Appendix C.** *Sample Transcript*

**Interview Transcript – Focus Group 2**

*"Communicating the Silent Disease"- Thesis* Interview, Lund – 25th of March 2026, 10:00
Total Interview time: 01:33:41

I – Interviewer
M – "Miriam"
E – "Elise"
J – "Jules"

**I:** Perfect. Okay, I thought we would start with a little introduction round. I've already kind of started. I thought we could go around, and then I have a little sheet. Here. So maybe your name, your pronouns, your age, your "profession", I guess, and something that you like to do for fun. Who would like to start?

**E:** I can start. My name is Elise, she/her. I'm 23 and a law student. And I like to knit. That's fun.

**M:** I am Miriam, I'm 21, and I'm studying English. And I also like to knit *(laughs)*.

**I:** Oh! *(laughs)*

**J:** I'm Jules, my pronouns are she/they, I am 24. I am a gender studies graduate and a waitress at the moment, and I like to watch a lot of movies.

**I:** Nice. Thank you, perfect. Right, now that we have gotten to know each other a little bit better, let's start talking about the topic that we're here for. Can each of us – sorry, can each of you tell us a little bit about your endometriosis journey?

**J:** I mean, I can start. Mine is, like I told you, it's suspected. I don't have a diagnosis. It's been a while since I've had, like, you know, crazy pains and everything that goes with it. But I was always a bit too lazy to get into the diagnosis of it all, because it lasts forever *[the other participants nod their heads]*. But yeah, I recently saw the doctor for something more like maybe IBS related, and they were like "well, maybe". So, I got a diagnosis of IBS, but then they were like, "okay maybe you do just have endometriosis". So, I'm sort of starting the diagnosis right now. Yeah

**I:** Mm-hmm.

**M:** I have diagnosed because, yeah, I've always had the crazy pains and a lot of bleeding ever since I started when I was like 13. But I got the diagnosis pretty early because I was 18. But that was because I developed chronic pain. So, I was basically in the hospital the whole time. And we basically had to force them to do something.

**E:** Yeah. I've had quite bad period pains since I first started getting my periods when I was 12, I think. And I was in contact with health care about it. And then I got on the pill and then the implant here. And then it kind of got better.

**J:** Does the implant help? Does it have hormones in it?

**E:** Yeah, it has hormones in it. So, it used to be really bad, and now I think it's okay. And then I never really sought the diagnosis because when I googled as well, it's mostly like, the treatment is hormones.

**J:** Yeah.

**M:** Yeah.

**E:** But I've also – now I read some about endometriosis like in connection to this [the focus group]. And it seems like nausea is quite a common symptom of endometriosis as well, and I've had like troubles with nausea for quite a few years, but like in periods. And I don't know, started thinking about that as well in connection to – yeah.

**J:** Yeah. I also literally today just got started on the pill because I had an appointment yesterday with a midwife and so she – it wasn't as extensive as I thought it would be, like, talking about endometriosis. We didn't really address it that much. She was just like, "Okay, there is a pill. You can try that and see if that works for you". So hopefully that helps because recently it's been getting even, I feel like, more painful and worse, and I don't know how to manage it so. And I've just started a job as well, so now I'm like, okay it's not really classes that I can take off. I need to show up for work and do it so, yeah.

**E:** Yeah. Yeah, my pains got better compared to how they were, but my periods got a bit weird, so that can happen. And it's been different every time I got them because I'm on my like third one now, like, the hormone implant. And it's been different every time. Like one time I changed it, and I had a period for like 2 months.

**J:** Two months?

**E:** Yeah.

**J:** Oh wow. Fun *(irony)*.

**E:** Yeah.

**I:** Has that happened to you as well? [directed at Miriam, who was nodding her head]

**M:** Yeah, I've tried the implant, the, what's it called? – the spiral, I think. And the mini pills, because my dad had a stroke when he was young, so I couldn't have the combination. But I developed chronic pain <u>from</u> the hormonal treatment.

**E:** Okay, oh.

**M:** And even when I stopped it, it did not go away. So that made me think also even more, like, the only treatment they want is the hormonal treatment, but I get so much worse on that. So, I just, I don't get help from the endometriosis team anymore because they're like, "yeah, but you need to do the hormonal treatment, in order to do something".

**E:** Yeah, I feel like that's often the – I've only had contact with the Ungdomsmottagning[6], with the youth healthcare center, I guess. And they are basically like, "Oh, they have this issue? Okay, you can get hormone treatment". Like, that's it. Because I came there and I was like, okay, I can't get out of bed some months, I'm sick from school, like every month, because I have these pains and they're like, "Okay, you can get that pill". Yeah. And that's it.

**M:** There is two, basically, endometriosis specialists, who work at Ungdomsmottagningen in Skåne. I don't know specifically where they are, but I think if you want to, you could talk to your provider.

**E:** I can't go to Ungdomsmottagningen anymore.

**M:** Oh right.

**E:** They kicked me out *(laughs)* [because she turned 23]

*Everyone laughs*

**M:** Yeah, because I got referred to that person, and they helped me a bit.

**E:** Yeah. That's good.

**J:** Yeah, the hormonal treatment. I was also just reticent to go on the pill because I haven't been on the pill since I was 16, for my skin, for acne, that was a treatment. And I'm a little bit scared of how it's going to affect me, even long-term. Like, that's just the pill, like, it's just a scary thing, so, like, that's easily given, it's got lots of progesterone in it, and, yeah, I don't know how it's going to affect my body, specifically, so, yeah. Not a great treatment, I think, but we'll see.

**E:** Hope it's going to work out.

**J:** Me too *(laughs)*.

**I:** When you guys were looking for answers – like you had these symptoms, everything was a bit weird, you thought something was off. Where did you go look for information?

**E:** I googled. [everyone nods their heads in agreement]

---

[6] Ungdomsmottagningen: For young people between the ages of 12 and 22, who have questions about their body, STDs, sex, relationships, or birth control. They can also get support if they are feeling down and need someone to talk to. The visit is free, and the staff are bound by confidentiality. All of the staff members are knowledgeable about LGBTQ+ issues.

**J:** Yeah, yeah.

**M:** Yeah, that and my mom was a very diligent Googler. She was basically the one who, like, "oh, I heard of this". And I was like, okay, and started looking elsewhere.

**J:** Did you find it right away that it was endometriosis at the time, or?

**M:** I thought it fit very well. But from the very extreme chronic pain, it took almost six months, and that was like, I lived at the hospital. So, I had – yeah. But also, they thought I was so young, so they didn't want to do the operation, but they can't diagnose without the operation. So that was like a whole thing. And then they couldn't treat the pain because, well now, it's chronic. So, it's – then we would just be giving you an addiction. But before that, we don't know what the pain was caused by so we can't treat the pain. So it was, yeah, circular.

**I:** When was this? How old were you?

**M:** I was 18. So that was also just after COVID, and so my mom couldn't be with me all the time. But I was in so much pain, so we basically had to force the hospital to always have my mother there, because otherwise they would just tell me to go home.

**I:** Would you say that – Because I had the same question as you just asked, Jules – was it easy or was it difficult to find information on endometriosis?

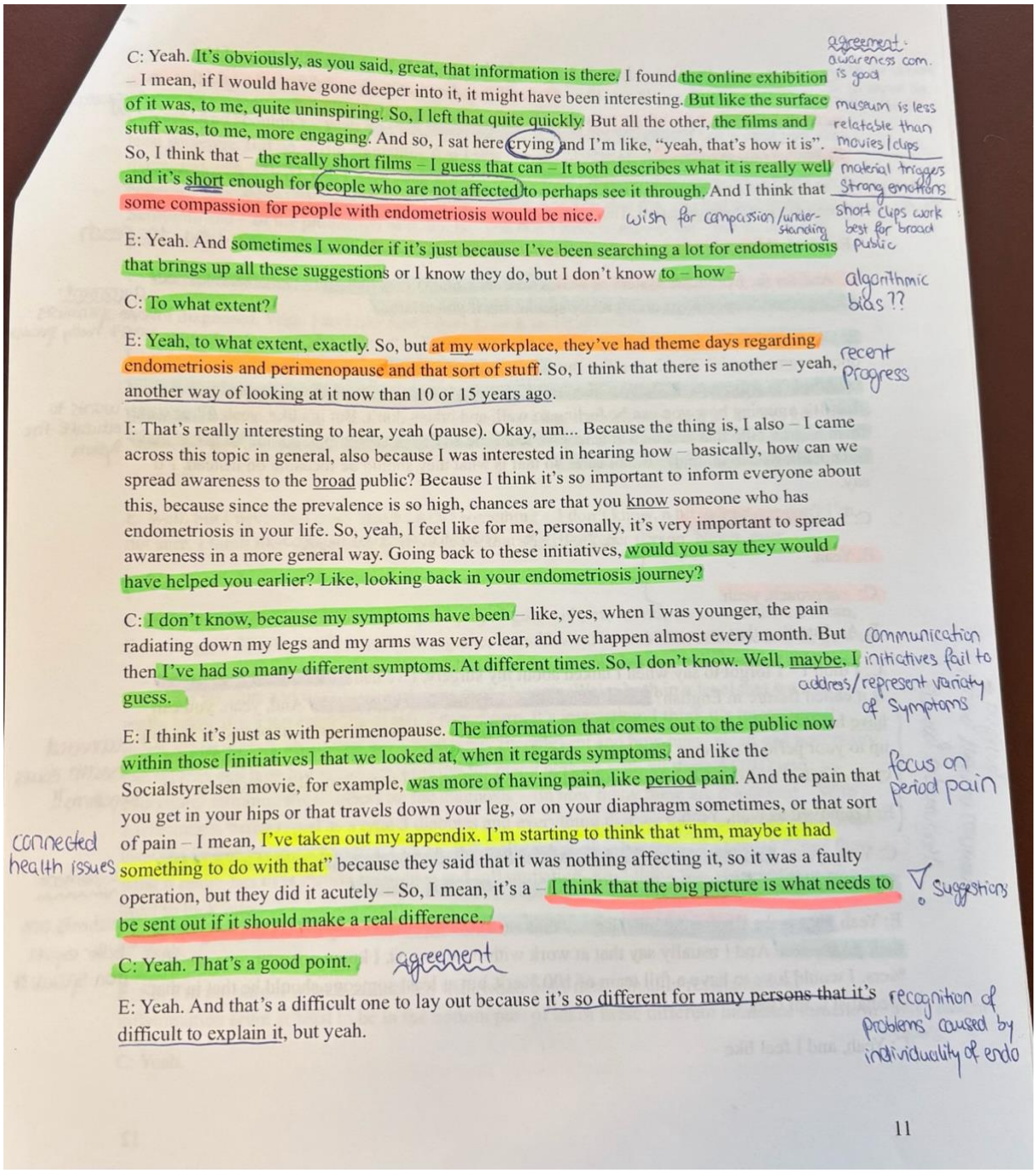
**E:** I thought it was quite easy when I googled. Like, I remember hearing about it quite early when I searched it up on the internet. But I think when I looked at the material, Socialstyrelsen came out with their videos and information stuff around 2018. And I think that's also when I got on the mini pill for the first time. So, I think there's been information when you google. I don't remember there being a lack of information online.

**J:** I think for me for a while as well, I just thought it was normal like to have like such pains and stuff. Because everybody says like, "your period is really painful". And everything else, like more chronic and more digestive and stuff, I associated that with my anxiety. And I thought that's what caused it and now I think it's probably just a blend of it all, maybe, or like very linked. So, I didn't look it up or I didn't think it fit me or that it was for me, for a while. And then I think until recently, a couple years or something, I was like, okay maybe I'm not making it up. Maybe it is like that, and it's me. And so, then I googled it. And TikTok was also really helpful, I'm not going to lie *(laughs).*

*Everyone laughs and nods their heads in agreement.*

**Appendix D.** *Excerpts of Coding & Mind Map*

## Analog Open Coding



C: Yeah. It's obviously, as you said, great, that information is there. I found the online exhibition – I mean, if I would have gone deeper into it, it might have been interesting. But like the surface of it was, to me, quite uninspiring. So, I left that quite quickly. But all the other, the films and stuff was, to me, more engaging. And so, I sat here crying and I'm like, "yeah, that's how it is". So, I think that – the really short films – I guess that can – It both describes what it is really well and it's short enough for people who are not affected to perhaps see it through. And I think that some compassion for people with endometriosis would be nice.

E: Yeah. And sometimes I wonder if it's just because I've been searching a lot for endometriosis that brings up all these suggestions or I know they do, but I don't know to – how –

C: To what extent?

E: Yeah, to what extent, exactly. So, but at my workplace, they've had theme days regarding endometriosis and perimenopause and that sort of stuff. So, I think that there is another – yeah, another way of looking at it now than 10 or 15 years ago.

I: That's really interesting to hear, yeah (pause). Okay, um... Because the thing is, I also – I came across this topic in general, also because I was interested in hearing how – basically, how can we spread awareness to the broad public? Because I think it's so important to inform everyone about this, because since the prevalence is so high, chances are that you know someone who has endometriosis in your life. So, yeah, I feel like for me, personally, it's very important to spread awareness in a more general way. Going back to these initiatives, would you say they would have helped you earlier? Like, looking back in your endometriosis journey?

C: I don't know, because my symptoms have been – like, yes, when I was younger, the pain radiating down my legs and my arms was very clear, and we happen almost every month. But then I've had so many different symptoms. At different times. So, I don't know. Well, maybe, I guess.

E: I think it's just as with perimenopause. The information that comes out to the public now within those [initiatives] that we looked at, when it regards symptoms, and like the Socialstyrelsen movie, for example, was more of having pain, like period pain. And the pain that you get in your hips or that travels down your leg, or on your diaphragm sometimes, or that sort of pain – I mean, I've taken out my appendix. I'm starting to think that "hm, maybe it had something to do with that" because they said that it was nothing affecting it, so it was a faulty operation, but they did it acutely – So, I mean, it's a – I think that the big picture is what needs to be sent out if it should make a real difference.

C: Yeah. That's a good point.

E: Yeah. And that's a difficult one to lay out because it's so different for many persons that it's difficult to explain it, but yeah.

agreement · awareness com. is good

museum is less relatable than movies/clips

material triggers strong emotions

wish for compassion/understanding

short clips work best for broad public

algorithmic bias??

recent progress

communication initiatives fail to address/represent variety of symptoms

focus on period pain

connected health issues

suggestions

agreement

recognition of problems caused by individuality of endo

11

**Coding Mind Map on *Miro*:** Link

**Appendix E.** *Consent Form & Confidentiality Agreement*

LUNDS UNIVERSITET

**Researcher:**
Caroline Nieder-Müller
ca2311ni-s@student.lu.se
Master's student, MSc in Media and Communication Studies
Department of Communication, Lund University

**Supervisor:**
Deniz Duru, PhD, Associate Professor
deniz.duru@iko.lu.se

## Consent to participate in a Master's Thesis in *Media and Communication Studies* at the Faculty of Social Sciences

### Invitation to participate

You are invited to participate in the research project conducted as part of the Master's thesis *Communicating the "Silent Disease": Media, Information-Seeking, and Lived Experiences of Endometriosis in Sweden [preliminary title]* at the Department of Communication at Lund University. The purpose of this study is to explore how people learn about endometriosis, how they seek information about the condition, and what role different media play in this process.

Participation involves taking part in a **focus group discussion** with a small group of participants. During the discussion, participants will be asked about their experiences with health information, their media use, and their reactions to health communication about the condition.

The discussion is expected to last approximately **2 hours**.

### Voluntary participation and withdrawal

Your participation in this study is voluntary. You may choose **not to answer any question,** and you may **withdraw from the study at any time without giving a reason**.

If you withdraw during or after the focus group, any data connected to you will be removed from the study as far as possible.

---

### Information on the processing of personal data

This thesis is a **student research project**, and only the personal data necessary for the study will be collected.

The following personal data will be collected (please provide below):

- Name: _____
- Age: _____
- Gender: _____
- Nationality: _____
- Profession: _____
- Education level: _____
- Any information shared during the discussion

Because the study concerns experiences with endometriosis, **sensitive personal data related to health may be discussed during the focus group**.

Your name will **not appear in the thesis**. All names will be **pseudonymized**, meaning they will be replaced with fictional names.

The focus group discussion will be **audio-recorded** in order to allow accurate transcription and analysis. The recordings will only be accessible to the researcher. Parts of the discussion may be **quoted anonymously** in the Master's thesis. Any quotations used will not contain identifying information.

All personal data and recordings will be stored securely on a **password-protected local hard drive**.

The data will only be used for the purposes of this Master's thesis and will **not be shared with third parties**.

All personal data will be **deleted after the thesis has been completed and graded**.

Lund University, Box 117, 221 00 Lund, Sweden, with organisation number 202100-3211 is the controller. You can find Lund University's privacy policy at www.lu.se/integritet

You have the right to receive information about the personal data I process about you. You also have the right to have inaccurate personal data about you corrected. If you have a complaint about our processing of your personal data, you can contact our Data Protection Officer at dataskyddsombud@lu.se. You also have the right to lodge a complaint with the supervisory authority (the Data Protection Authority, IMY) if you believe that I am processing your personal data incorrectly.

LUNDS UNIVERSITET

**Researcher:**
Caroline Nieder-Müller
ca2311ni-s@student.lu.se
Master's student, MSc in Media and Communication Studies
Department of Communication, Lund University

**Supervisor:**
Deniz Duru, PhD, Associate Professor
deniz.duru@iko.lu.se

## Confidentiality Agreement for the participation in a Master's Thesis in *Media and Communication Studies* at the Faculty of Social Sciences

In order to respect the privacy of all participants in the thesis project *Communicating the "Silent Disease": Media, Information-Seeking, and Lived Experiences of Endometriosis in Sweden [preliminary title]* all parties are asked to read and sign the statement below. If you have any reason not to sign, please discuss this with Caroline Nieder-Müller, the researcher of this study.

I, _____, agree to maintain the confidentiality of the information discussed by all participants and researchers during the focus group discussion.

| | |
|---|---|
| Location | Signature |
| Date | |