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Nurses’ role in minimizing medical gaslighting and maximizing awareness in endometriosis care

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ABSTRACT

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Endometriosis has become a more frequent topic in the media and health care circles over the past decade, leading to improved recognition. However, the main issues reported by patients have largely remained unchanged, with a complex chain of reasons behind them. This bachelor’s thesis examines two of these reasons: medical gaslighting and lack of awareness, as well as the correlation between them. This thesis aims to evaluate how nursing professionals, within their scope of practice, can help increase awareness and, in turn, reduce the medical gaslighting that many patients still encounter. The objectives set to achieve this include gathering relevant research on patient experiences in endometriosis care, systematically analysing these studies, identifying prevalent themes, and discussing the findings from a nursing perspective. The research question guiding the analysis was: “*What roles and functions could be undertaken by nurses to address the systemic and educational shortcomings and improve patient-centered care in endometriosis management*?”

This bachelor’s thesis was conducted as a descriptive literature review, with the results interpreted using qualitative content analysis. The data search was performed in the EBSCO CINAHL database, along with secondary sources, using various search prompts and combining the results. Nine articles, published between 2018 and 2023 from different countries, were selected for review.

The results indicated that medical gaslighting, as well as lack of awareness and understanding of endometriosis among health care providers, patients, and the public, remain persistent obstacles to optimal care. While these emerged as the two main themes in the content analysis, the subcategories highlighted issues that could potentially be addressed by further involving nursing professionals in the management of endometriosis, particularly in the areas of information dissemination and communication.

Key words: endometriosis, medical gaslighting, awareness, patient-centered care

CONTENTS

GLOSSARY

dissemination	“an active approach of spreading evidence-based interventions or knowledge to the target audience via determined channels using planned strategies [..] therefore defined as a systematic approach to determining effective strategies to communicate evidence with target audiences, for the purpose of changing these dissemination outcomes” (Turon et al., 2023)
endometriosis	a disease characterized by the presence of endometrium-like epithelium and/or stroma outside the endometrium and myometrium, usually with an associated inflammatory process (International Working Group of AAGL, ESGE, ESHRE and WES et al., 2021)
endometrium	the mucous membrane lining the uterus (Merriam-Webster, n.d.)
ESHRE	The European Society of Human Reproduction and Embryology
gender bias	“usually [..] unintended, but systematic neglect of either women or men, stereotyped preconceptions about the health, behavior, experiences, needs, wishes and so on, of men and women, or neglect of gender issues relevant to the topic of interest” (Hamberg, 2008)
hysterectomy	surgical removal of the uterus (Merriam-Webster, n.d.)
lived experience	“the unique insights and perspectives [..] the first-hand knowledge and understanding individuals acquire by living with a specific health condition” (Patient Experience Agency, 2023)
medical gaslighting	“an act that invalidates a patient's genuine clinical concern without proper medical evaluation, because of physician ignorance, implicit bias, or medical paternalism” (Ng et al., 2024)

1 INTRODUCTION

The story of endometriosis and the lived experiences of those affected by it present a fascinating narrative – one that spans from remarkable human resilience to striking absurdities in health care worldwide. Few illnesses are both as widespread and controversial as endometriosis, with challenges including historically rooted gender bias, conflicting medical opinions, public misconceptions and patient misinformation, and a critical lack of access to effective, evidence-based care - even in high-income countries (Endometriosis UK, 2024; Hooper, 2024).

Endometriosis is commonly estimated to affect around 190 million women of reproductive age worldwide (WHO, 2023). However, this figure does not account for women affected outside of the reproductive age group (Rosser, 2011). Similarly, it overlooks the potentially large number of undiagnosed cases, as indicated by diagnostic delay data – many patients are forced to wait for years to receive an accurate diagnosis (Lindeman, 2023, p. 9; Kirk et al., 2024). Additionally, endometriosis also occurs in transgender and non-binary individuals, and in extremely rare cases, has been identified in male patients (Lindeman, 2023, p. 12), further contributing to its underreported prevalence.

A major barrier to a transparent understanding of endometriosis is the long-standing issues with reliable, up-to-date information surrounding the condition. This had led to the continued use of outdated theories on its pathogenesis and treatment, a widespread misunderstanding of symptoms typical for endometriosis among both medical professionals and the public, and even the persistence of the incorrect definition of endometriosis in both scientific and media texts (Hudson, 2021). While the distinction between defining endometriosis as the presence of ‘endometrial cells’ versus ‘endometrial-*like* cells’ outside the uterus may seem insignificant, this single word directly impacts the understanding of the disease’s origins and, consequently, how effective the treatment chosen based on this understanding will be (Cooper, 2018; Taylor et al, 2021). For many patients, this distinction can determine whether they will endure years of unaddressed suffering that could be avoided with better awareness and understanding of endometriosis.

While many systemic issues – such as improving access to effective treatment and increasing endometriosis-related education for both professionals and the public – require action from governments, health care systems, and educational institutions (Kirk et al., 2024), some aspects could be addressed on a small scale. Traditionally, medical professionals have been considered reliable sources of accurate health information. However, this has not been the case with endometriosis. Reports of misinformation from health care providers have encouraged the efforts of patient advocacy groups, content creators raising awareness, and non-governmental activists - many of whom were driven to activism by their own experiences with inadequate medical care (Hudson, 2021; Seo et al., 2025).

Research, including the studies analysed in this bachelor's thesis, clearly highlights the need for improvements in endometriosis-related education for physicians and the shortage of endometriosis specialists. Additionally, nurses seem to be an underutilized resource who have the potential to play an important role within their scope of practice. They could contribute to enhancing the understanding of endometriosis, support a more holistic approach to care, and improve the overall patient experience. This, in turn, would allow the endometriosis specialists to focus on the more technical aspects of treatment, creating a more comprehensive and integrated approach to care together. As such, the research question set to guide the analysis was: “*What roles and functions could be undertaken by nurses to address the systemic and educational short-comings and improve patient-centered care in endometriosis management*?”

2 THEORETICAL BACKGROUND

2.1 What is endometriosis – and what it is not

Endometriosis is a chronic, inflammatory, systemic disease defined as the presence of endometrial-*like* tissue outside the uterus. Endometriosis lesions typically cause a progressive inflammatory reaction, leading to adhesions within the affected organs or even between separate structures and organs. The lesions are classified into 3 major groups: superficial peritoneal lesions, ovarian endometriotic cysts (endometriomas) and deep-infiltrating endometriosis. (ESHRE, 2022, p. 6, pp. 85-86)

Despite being frequently labelled as a strictly gynaecological condition, a women's illness or a menstrual disorder, and often considered confined to the pelvic cavity, endometriosis has been documented in nearly all organ systems, including the lungs, heart, kidneys, diaphragm, central nervous system (CNS), and even the eyes and brain. The most commonly affected areas, however, include the ovaries, fallopian tubes, bladder, bowels, peritoneum, and the recto-vaginal cul-de-sac (the space between the posterior wall of the uterus and the rectum). (Andres et al., 2019) Furthermore, even though some patients experience symptom fluctuations according to the menstrual cycle, for others the symptoms are persistent throughout the cycle, irregular or associated with certain triggers, whereas some patients experience no symptoms (Myers, 2020; WHO, 2023).

As previously mentioned, the correct endometriosis definition that is increasingly adopted due to advocacy efforts, distinguishes the disease being caused by tissue histologically similar, but not identical to the endometrium (the inner layer of the uterus). An accurate understanding of its true characteristics is essential for a more efficient approach to treatment and connected to more promising research outcomes. Endometriosis is not a uterine disease (unlike its related condition – adenomyosis). Acknowledging this distinction and understanding that endometriosis lesions behave differently from normal endometrial tissue is crucial in improving endometriosis care. (Guidone, 2020, p. 270; International Working Group of AAGL, ESGE, ESHRE and WES et al., 2021) The failure to base treatment plans on a comprehensive understanding of the disease has led to years of diagnostic delays and ineffective treatment, a widespread experience among patients (Broster, 2020; Guidone, 2020).

2.1.1 Symptoms

As a systemic disease, endometriosis can present with a variety of symptoms. The ones commonly mentioned in the literature are dysmenorrhea (pain during menstruation), dyspareunia (pain during intercourse), and dyschezia (pain during bowel movement). While many patients do experience one or more of these symptoms, a deeper understanding of the disease highlights that endometriosis-related symptoms can vary widely and are not necessarily limited to the reproductive system. Similarly, while some patients might suffer from many symptoms, others might have one or none and might only learn of their endometriosis as an incidental finding. (WHO, 2023) Furthermore, the onset of symptoms varies among patients as well – the documented range is from before or during puberty throughout the reproductive age, to menopause (Rosser, 2011).

Besides the aforementioned symptoms, patients have also reported the following:

- Abdominal pain, which may be associated with menstruation or occur at any time during the menstrual cycle (observed in 50-80% of women with pelvic pain) (Saunders & Horne, 2021; Taylor et al., 2021; Gete at al., 2023).
- Urinary or gastrointestinal pain, discomfort or dysfunction, for example, bloating, nausea or painful digestion, diarrhea, constipation or both (again – during menstruation or occurring independently) (Ek et al., 2015; Saunders & Horne, 2021; Gete et al., 2023).
- Infertility, difficulty conceiving or pregnancy loss (up to 50% of primary infertility cases are associated with endometriosis) (Taylor et al., 2021; Bonavina & Taylor, 2022).
- Heavy menstrual bleeding or irregular bleeding throughout the cycle (Saunders & Horne, 2021; Gete et al., 2023).

- Fatigue and weakness, often due to an immune response that produces inflammatory cytokines, resulting in energy loss, brain fog and other symptoms (Taylor et al., 2021; Gete et al., 2023).
- Musculoskeletal pain, particularly lower back pain and sciatica, which can radiate down the legs (Gete et al., 2023; The Center for Endometriosis Care, n.d.).
- Existing comorbidities (allergies, migraines, asthma) and a scientifically proved risk – associated with endometriosis – of cardiovascular diseases, cancer and autoimmune diseases (Saunders & Horne, 2021; Kvaskoff, 2024).

2.1.2 Pathogenesis

Multiple theories on the pathogenesis of endometriosis have been proposed over the past century, however, none of them fully explain its causes or the mechanisms of progression yet. The oldest and most enduring theory, Sampson’s theory of retrograde menstruation, has been in use since the 1920s. This theory proposes that endometriosis lesions are normal endometrial tissue that has been shed during menstruation and then flushed back into the pelvis by a common phenomenon called retrograde menstruation (Saunders & Horne, 2021). While some aspects of this theory persist, it fails to explain the disease’s pathogenesis based on the histological definition (‘*tissues similar, but not identical, to the endometrium*’) and some of the clinical observations, such as extragenital endometriosis (Redwine, 2002; Koninckx et al., 2019). Unfortunately, despite the development of more up-to-date theories, some physicians continue to rely solely on this explanation, contributing to diagnostic delays and ineffective treatments (Guidone, 2020).

Currently, the epigenetic/genetic and stem cell theories have come closest to explaining all aspects of both common and rare types of endometriosis. However, further research is needed to strengthen the findings and integrate them into treatment. Other aspects of the disease have been explored through the metaplasia, lymphatic spread, genetic, Müllerian and immune theories, among others.

A widely accepted view suggests that no single theory fully accounts for all characteristics of endometriosis; rather, a combination of multiple theories is likely responsible. (Koninckx et al., 2019; Saunders & Horne, 2021; Taylor et al., 2021)

2.1.3 Diagnosis

Receiving a diagnosis of endometriosis has long been recognized as a challenge from the patients' perspective. Factors such as medical misinformation and high threshold for suspecting endometriosis are among the largest contributors. Studies report significant diagnostic delays, averaging between 5 to 10 years, which are associated with increased economic burden and more advanced symptoms. (Surrey et al., 2020; Pino et al., 2023)

As with any diagnostic process, suspicion of endometriosis (or the ruling out of other conditions) should arise from a comprehensive clinical evaluation, including a detailed symptom history, medical background, and physical examination. However, according to the ESHRE (2022) guidelines, further investigation should be undertaken even if initial suspicion is low, as symptoms alone are not a reliable predictor of endometriosis.

Currently, no reliable blood test or diagnostic biomarker exists for detecting endometriosis. While the CA-125 test (also known as the ovarian cancer marker) is sometimes used due to its elevation in some endometriosis patients, guidelines advice against using it, as normal levels do not necessarily rule out endometriosis, and elevated levels can occur in other conditions. This, however, remains an active topic of endometriosis research. (ESHRE, 2022; Burghaus et al., 2023)

The use and effectiveness of visual diagnostics depends on the type and location of lesions. The most commonly used imaging techniques are transvaginal ultrasound (US) and magnetic resonance imaging (MRI). ESHRE (2022) guidelines recommend incorporating both into the diagnostic process, while recognizing that negative imaging results do not conclusively exclude the disease. Other types of imaging techniques have not been researched and applied as widely.

If imaging is inconclusive but symptoms persist, with or without empirical treatment, laparoscopy is recommended, provided it is performed as both an exploratory and a curative surgical intervention. In the recent past diagnostic laparoscopy was considered the gold standard in diagnosis of endometriosis; and laparoscopy is still the only way to acquire biopsy material for histological analysis of tissue, which in turn can confirm endometriosis conclusively. However, the development of technology in visual imaging, the risks associated with surgical interventions and the limited availability of highly specialized endometriosis surgeons are among the reasons why the current guidelines do not recommend laparoscopy solely for diagnostic purposes in all cases. (ESHRE, 2022; Pascoal et al., 2023)

2.1.4 Treatment

Currently, there is no definitive cure for endometriosis. Existing treatments focus on symptom management and improving quality of life, but none can fully guarantee symptom elimination or prevent recurrence. (WHO, 2023) Treatment options fall into two main categories: surgical and pharmaceutical, often supplemented by complementary approaches such as physical therapy, dietary and lifestyle changes, acupuncture and exercise, among others. However, due to limited research evidence, no official recommendations can be made for alternative treatments, as their potential benefits and risks remain uncertain. (ESHRE, 2022)

The choice of treatment is usually based on patient’s symptoms, preferences, and life circumstances, along with the physician’s guidance and treatment availability. Pain and infertility are often the leading factors for the choice of treatment. Depending on whether the patient’s main goal is pain relief or fertility improvement, either a surgical or hormonal treatment – or a combination of both – may be recommended. In some cases, both concerns are equally important, requiring a treatment plan that effectively addresses both aspects. (ESHRE, 2022).

Pharmaceutical therapy is most often hormonal. Aside from that, long-term use of analgesics is not uncommon among endometriosis patients, including paracetamol, nonsteroidal anti-inflammatory drugs, or even opioids, both of which present with risks for long-term use. Neuromodulators is another group of medications sometimes prescribed by primary care physicians in the management of endometriosis pain by modulating the response of CNS to it. (Taylor et al., 2021; ESHRE, 2022)

Hormonal treatment, on the other hand, includes hormonal contraceptives and GnRH agonists/antagonists – medications that affect gonadotropins and sex hormones by activating or blocking them. Hormonal contraception, mostly progestin preparations, reduce estrogen in turn lowering the inflammatory reaction, but are not effective or effective enough in some patients. GnRH agonists work by suppressing ovarian function and normal menstrual cycle, which in turn induces chemical menopause and therefore diminishes pain symptoms. However, as the medication essentially stimulates chemical menopause, the side effects are a large downside of this treatment – lowered bone density and loss of bone mass, hot flushes, headaches, vaginal dryness and spotting, mood and sleep disturbances. (Saunders & Horne, 2021; Taylor et al., 2021) For this reason, only short-term use (for 6-12 months, depending on the treatment regimen) or use as a second line treatment (e.g. if hormonal contraceptives have been ineffective) is recommended. It can also be used as an adjuvant therapy before or after surgical intervention to improve the outcomes, or to prevent recurrence. (ESHRE, 2022) GnRH antagonists work in a similar fashion and with similar side-effects, but a slightly better outlook at recuperating after the end of the treatment and the side-effects being better tolerated. Hormonal therapy is considered a suitable treatment for disease management for patients who do not express the wish to conceive, as they block the menstrual cycle. (Taylor et al., 2021) There is no evidence that one hormone treatment would be superior to another (ESHRE, 2022). Nevertheless, increasing numbers of patient advocates and many endometriosis specialists are speaking up against the use of this method of treatment, because of the side-effects and because these medications only mask the symptoms (Guidone, 2020, pp. 270-271; Lindeman, 2023, pp. 149-150).

Surgery – when performed by an expert endometriosis surgeon as opposed to a general obstetric gynecologist – remains the most reliable and successful treatment option for symptom management (Bougie et al., 2025). In endometriosis surgery, time, research and technological advancements have given room for laparotomy to be replaced by laparoscopy, and conventional laparoscopy to be replaced by robotic laparoscopy. As such, expert endometriosis laparoscopy is not a cheap treatment method, and in many countries this type of treatment is not reimbursable or even available, at least in the public sector. (Andres et al., 2022) The goal of endometriosis surgery is to remove endometriosis lesions and separate any adhesions that may have formed. Additionally, an important part of the surgery is to acquire tissue biopsy for histological analysis. (ESHRE, 2022) Two types of surgical approaches are used in endometriosis operations: excision (removing diseased tissue) and ablation (destroying diseased tissue). While ablation may still be useful in some cases, particularly in minimal, superficial disease, it is agreed that excision – performed by an appropriately trained and highly skilled endometriosis surgeon – is superior (Mackenzie, 2023; Isaac et al., 2025). It allows the diseased tissue to be removed completely, as opposed to ablation that destroys only the visible parts and may easily leave disease behind where not visible. Additionally, ablation damages the tissues so profoundly that biopsy is often impossible. (Guidone, 2020, p. 271; Lindeman, 2023, p. 231) The two methods are often compared by the analogy of destroying weeds – where ablation burns them, leaving the roots behind, and excision digs them up – root, stem and flower. The reported outcomes, including complications, postoperative pain and recurrence of endometriosis justifiable place expert performed excision in favor of ablation (Isaac et al., 2025). That being said, it is important to remember that no treatment method is able to guarantee a complete removal of disease or avoidance of recurrence.

Since this thesis is focused on the ways in which misinformation can harm patients, it is important to note that medical myths and prejudices are prevalent in endometriosis care, and some of them are still being suggested as strategies to treat the disease. Such approaches are harmful and can be damaging not only to the patient’s health but also result in negative repercussions to their mental health and general coping (Guidone, 2020, p. 270; Sirohi et al. 2023). One such proposal is suggesting pregnancy as a way to treat endometriosis. While many patients might be looking to get pregnant and even seek help with the infertility aspect of endometriosis (for whom this advice might propose an added layer of desperation as pregnancy is not always possible to achieve even after successful treatment), many might be made desperate enough by years of suffering to try it as a last course of action. (Guidone, 2020, p. 271; Lindeman, 2023, p. 149) ESHRE guidelines (2022) stand against recommending pregnancy for treatment, as research shows no evidence of pregnancy eliminating endometriosis lesions, nor does it always improve the symptoms or stop the progression. Accounts from some patients stating that endometriosis improved during pregnancy are likely to do with the shift in hormonal balance, however this practice is not supported by research and is highly controversial and surround with ethical challenges and implications of the gender health gap. (Leeners et al., 2018)

Another frequently misused intervention in endometriosis is the practice of performing hysterectomies. Such practice is associated with poor long-term outcomes, as endometriosis is by definition located outside of the uterus, and – unless the patient also suffers from adenomyosis which occurs within the uterus and unless removal of the endometriosis lesions is performed – are not likely to result in a significant improvement of symptoms (Guidone, 2020, p. 271). Furthermore, if the ovaries are removed alongside the uterus, early menopause and the possible need for hormone replacement therapy are factors to consider (ESHRE, 2022).

2.2 Nursing within endometriosis care – global experiences

While information on the extent of nurses' involvement in endometriosis care globally is scarce, it is reasonable to assume that, given the range of nursing practice and the prevalence of the disease, nurses play a role at all levels of endometriosis care. Their qualifications enable them to contribute significantly to the multidisciplinary management of endometriosis by providing patient education based on a correct understanding of the disease, offering support, and coordinating care. The NICE guideline on endometriosis diagnosis and management (NICE, 2024) from the United Kingdom recognizes nurses as an integral part of endometriosis care. It specifically identifies practice and school nurses for community services, gynecology specialist nurses with expertise in endometriosis for general gynecology services, and endometriosis specialist nurses for dedicated endometriosis centres. Some of the responsibilities that nurses across these specializations may undertake include conducting detailed clinical histories, listening to patients’ accounts with trust and empathy, discussing potential interventions based on guidelines and evidence, and educating patients. Nurses are also at the forefront of recognizing symptoms and considering how the disease affects women’s coping mechanisms and quality of life – factors that should be accounted for when developing treatment plans. (Norton & Holloway, 2020)

These responsibilities align with the endometriosis nurse specialist role, established in the UK in 2013 in response to ESHRE’s recommendation to create dedicated endometriosis specialist centres. Nurse specialists serve as a link between patients and the specialist team, and some of their tasks include carrying out initial assessment, offering information, and evaluating patients’ quality of life, as well as conducting outpatient follow-ups, including post-operatively. (Norton et al., 2020) It is a senior role and requires nurses to continuously update their knowledge and recognize the importance of following research and have insight into all features of caring for endometriosis, including the social and political aspects of it (Royal College of Nursing, 2015).

In Australia, a similar role – the endometriosis nurse coordinator – has been implemented in recent years. As the first point of contact for patients diagnosed with or suspected of having endometriosis, the nurse coordinator conducts initial discussions to document the patient's experience and develop a care plan. These professionals also provide pre- and post-operative support while empowering patients with reliable education on the multidisciplinary approach to endometriosis management. (Tyson et al., 2024) Furthermore, a scholarship program has been established to train endometriosis specialty nurses, aiming to improve access to highly trained specialists in rural areas (Nizeti, 2024).

Australia has also led the way as the first country to implement a National Action Plan for Endometriosis care, which calls for greater responsibility for nurses. The plan proposes active roles for nurse-educators, practice nurses, nurse practitioners, and endometriosis specialist nurses in improving patient care. Additionally, educational programs based on the ‘train the trainer’ principle are proposed to ensure better understanding of endometriosis in all levels of health care and providers of all specialist backgrounds. In addition to the standard pelvic examination and ultrasound, an extensive diagnostic meeting involving a discussion about the patient’s holistic experience and family history is suggested, leading to clinical pathways within multidisciplinary teams. (Australian Government Department of Health, 2018) While systemic challenges such as lack of research funding and the economic burden of the disease persist, progress has been made in reducing diagnostic delays and de-normalizing abnormal symptoms since the plan’s implementation (Armour et al., 2022).

A notable example of general practice nurses raising awareness is the School Nurse initiative, carried out by the Centre for Endometriosis Care in Atlanta, USA, in partnership with the production team behind the endometriosis documentary *Endo What?* As part of the campaign, school nurses across the country received educational toolkits with accurate, evidence-based information and resources like lesson plans for teachers. The rationale behind this campaign saw school nurses as instrumental in the recognition of the early signs of endometriosis and preventing unnecessary suffering and years of delay in diagnosis (Wershler, 2017) in students who may not know that their symptoms are not in line with what normal menstruation should feel like.

Calls for specialized training in endometriosis have been made by professionals involved in endometriosis care. A report by Endometriosis UK has advocated for integrating menstrual health and endometriosis education into all professional healthcare courses and called on governing bodies to expand access to such training. Additionally, the report emphasized the need to improve nurses’ and paramedics’ skills in recognizing and managing endometriosis. Healthcare providers already working in the field stress that certain narratives presented by patients – especially when brought up repeatedly – should always raise suspicion for endometriosis rather than being dismissed or misattributed. (Church, 2024)

3 MEDICAL GASLIGHTING

3.1 Gaslighting in medicine – manifestations and reasons

The term "*gaslighting*" describes situations where a person is led to question their own experience that they would usually have full confidence in. It occurs when another person (or groups and/or institutions) forces their own interpretation or portrayal onto an individual’s reality, causing them to second-guess their perceptions. (Barnes, 2023) In the context of healthcare, this results in the diminishment or dismissal of a patient’s lived experience, effectively undermining the expertise they have gained through embodied experience. Common indicators of medical gaslighting in patient-provider interactions include:

- Poor listening to the patient or frequent interruptions,
- Downplaying symptoms or misattributing them solely to factors such as age, weight, gender, identity, or lifestyle,
- Attributing symptoms to stress, anxiety, or other mental health factors,
- Hurrying through the appointment without giving adequate attention to the issue (Godman, 2024).

It is often assumed that a medical professional, with their extensive education and clinical experience, possesses greater expertise in all aspects of illness. However, this assumption fails to acknowledge the patient’s lived experience, which cannot be fully captured through formal education alone. An additional burden in this case can appear if the patient is a representative of a social group that is already marginalized, underrepresented, or presenting with health disparities, such as women, the elderly, people of colour, or LGBTQ+ individuals (Wise, 2022; Barnes, 2023). Additionally, medical gaslighting is a common phenomenon in conditions or patient groups that are poorly understood by the medical community or that lack sufficient scientific inquiry – one of the key reasons behind its occurrence (Barnes, 2023).

It is important to note that not all disagreement in patient care can be attributed to gaslighting. Professionals can make mistakes in clinical judgement the same way as patients can misinterpret their symptoms. Gaslighting happens when an authority person (in this case, a health care provider) uses a power position to invalidate the experiences that patients have lived through and question the legitimacy of their symptoms and complaints (Barnes, 2023).

Gaslighting between a physician and a patient tends to take the form of paternalism – the physician can assert their authority as a trained professional, dismissing the concerns as trivial or uninformed. When patients attempt to advocate for themselves – especially by presenting their own research – they may be met with condescending warning not to trust everything they read online. Their pain may be minimized, and their suffering misattributed to anxiety or hypochondria. (Lindeman, 2023, p. 258) The patients, in return, start to experience self-doubt, avoidance of health care, and distrust of the health care system, resulting in medical trauma (Shapiro & Hayburn, 2024). In extreme cases, the fear of having their concerns dismissed becomes one of patients' primary safety concerns regarding medical care (ECRI, 2025).

Physicians play a crucial role as leaders in healthcare; however, they are not the only professionals who may exhibit dismissive attitudes. Healthcare professionals, in general, hold positions of authority, and when gaslighting occurs – whether intentionally or unknowingly – it represents an abuse of that power. Eliminating this harmful practice requires time, systemic change, and a willingness to engage in open discussions among all stakeholders. Regarding nursing professionals, it is important to recall the ICN Code of Ethics for Nurses: "nurses are patient advocates, and they maintain a practice culture that promotes ethical behaviour and open dialogue". Additionally, it emphasizes that "nurses demonstrate professional values such as respect, justice, responsiveness, caring, compassion, empathy, trustworthiness and integrity". (ICN, 2021) Medical gaslighting indicates system-wide issues in health care that result in worse outcomes, diagnostic and treatment delays, and general distrust in health providers. Nurses are in a unique position to address this as their educational background is focused on a patient-centred, holistic approach, listening to and advocating for their patients and encouraging them to advocate for themselves. (LaMandre, 2025)

3.2 Medical gaslighting in endometriosis care

The complex nature of endometriosis creates favourable conditions for medical gaslighting to persist and remain widespread in endometriosis care. It affects women and addresses their pain as one of the symptoms (gender bias), among whom LGBTQ+ individuals and people of colour are widely represented (marginalized populations) (Wise, 2022). It revolves around complex and often highly individual symptoms (Hudson, 2021), the care provided is impaired by the lack of translational research and evidence-based medical education and there are notable hierarchies and specialization gaps present (limited knowledge of endometriosis across other medical specialties and general practice, widespread misconceptions in gynecology, and the scarcity of accessible, knowledgeable specialist care) (Guidone, 2020). Moreover, the historical mistreatment of endometriosis has established and normalized preventable suffering and misinformation and continued harmful approaches to treatment – it is proposed by research that a large proportion of those once diagnosed with “hysteria” have most likely suffered from endometriosis given the overlapping symptoms (Nezhat et al., 2012). If this were the case, Nezhat (2012) argues, it would represent “one of the most colossal mass misdiagnoses in human history, one that over the centuries has subjected women to murder, madhouses, and lives of unremitting physical, social, and psychological pain.”

Although hysteria is no longer a recognized medical diagnosis, many individuals who are ultimately diagnosed with endometriosis continue to face dismissive attitudes in medical settings. Patients frequently encounter questions about their stress levels or anxiety, well-intentioned but harmful remarks suggesting that pain is a “normal” part of a woman's health journey, and, in some cases, outright disbelief from healthcare providers regarding their symptoms and their severity. The tendency to perceive patients’ complaints as exaggerated or misinterpreted closely mirrors the historical mistreatment of gynecological conditions (Hudson, 2021).

The effects of medical gaslighting in endometriosis are alarming: delays in diagnosis and subsequent treatment lasting for years during which the disease can progress, ineffective treatment methods (Guidone, 2020; Hudson, 2021), financial burden both on an individual and societal level (Surrey et al., 2020), psychological toll and loss of quality of life, and medical trauma leading to mistrust in the health care system (Shapiro & Hayburn, 2024; LaMandre, 2025). Hearn et al. (2024) suggest improving communication (and communication skills, including advocacy and self-advocacy) between patients and health care providers, improving training in health care providers, and raising public awareness of the disease to facilitate access to help for people with endometriosis. The proposal to actively draw attention to professionals gaslighting patients (Ng et al., 2024) agrees with the suggestion to the patients to seek second opinions where necessary (Godman, 2024), instead of being continuously dismissed. Furthermore, improving standards of care, guidelines, and funding of research as well as re-evaluating research priorities have been noted as important issues to solve to address gaslighting (Guidon, 2020; Hudson, 2021; Gainty, 2023).

4 AIM, OUTCOME, AND OBJECTIVES

The aim of this thesis is to evaluate how nursing professionals, within their scope of practice, can help increase awareness and, in turn, reduce the medical gaslighting that many patients encounter when seeking diagnosis and treatment of endometriosis.

The planned outcome of this thesis is to provide an insight into which areas of information and communication regarding endometriosis require the most need for intervention and why raising awareness of endometriosis and its characteristics with evidence-based, up-to-date information may help challenge this. An additional outcome is bringing attention to what medical gaslighting is, and how it manifests itself in the context of an under-researched and poorly understood medical condition representing marginalized patient groups. The results gathered may be of use and interest to other students and professionals in health care wishing to improve their understanding of this condition and the care provided to patients.

The objectives set to achieve this include gathering relevant research on patient experiences in endometriosis care, systematically analysing these studies, identifying prevalent themes, and discussing the findings from a nursing perspective.

The research question set to guide the analysis was: "*What roles and functions could be undertaken by nurses to address the systemic and educational shortcomings and improve patient-centered care in endometriosis management*?"

5 METHODOLOGY

5.1 Descriptive literature review

This thesis was conducted as a descriptive literature review. The key purpose of a descriptive review is to evaluate how a body of knowledge within a specific research area exposes patterns or trends concerning established concepts, approaches, or results, as the research phase of it follows a structured and clear plan of action (Paré & Kitsiou, 2017). It does not aim to produce original research, instead focusing on systematic analysis of existing research. The benefits of a descriptive literature review are providing an in-depth insight into the study field of interest and material for initiating new hypotheses and research questions (Taherdoost, 2023), as well as identifying potential gaps in research and strengthening previous knowledge (Grant & Booth, 2009). The downside of descriptive literature reviews is that they tend to focus on a surface-level, descriptive overview of a topic and may not delve into the cause-and-effect links related to the research question (Snyder, 2019; Taherdoost, 2023). Additionally, it is more open to bias, as the focus is narrow, and authors may select research that supports the intended result (Grant & Booth, 2009).

The research process of this literature review followed the structured approach outlined by Paré & Kitsiou (2017) and included the following steps:

- Defining the research question and setting the aim and objectives,
- Reviewing existing literature,
- Screening studies for inclusion criteria,
- Evaluating the quality of primary research,
- Collecting relevant data and conducting data analysis.

A descriptive literature review is particularly valuable in nursing research not only because of its focus on the current outlook of a given issue but also because the research process followed in a literature review is highly applicable to reviewing research to implement it for practice. As reviews provide an extensive outlook on trends and issues on a wider scope, they may prove valuable in re-evaluating and adjusting current care practices. For nurses to apply evidence in practice, they must be able to recognize, evaluate critically, and integrate research findings (Smith & Noble, 2015).

5.2 Systematic data search

An integral part of the data search process is establishing the research question as a step towards identifying search terms. In this case, PICO framework (Population/Patient, Interest/Exposure, Context, Outcome) was used as a tool in the shaping of the research question (Brice, 2023). The initial question was intended to focus on the nurse’s role in holistic endometriosis care, however, it was found to be too broad for the scope of the bachelor's thesis, and this finding was confirmed by preliminary research article identification. The final research question focuses on one of the most prominent and persistent issues that is also applicable to the nursing scope of practice within endometriosis care, and it was formulated to consider the patients as the main benefactors. As such, the article search also primarily considered patient experiences.

Initially both EBSCO Cinahl and PubMed databases were considered for the article search, however, a preliminary search in PubMed revealed a large number of results irrelevant to the topic chosen and incompatible with the scope of a literature review. As a result, the final article search was conducted using EBSCO Cinahl database, and additional articles were identified from secondary sources before the article screening process. The keywords used for the search included “endometriosis” AND nursing/nurs*”, “endometriosis AND holistic care”, “endometriosis AND patient experience” to cover all aspects of the thesis topic and research question as set by the PICO framework.

The search was conducted based on inclusion and exclusion criteria. A 10 year timeframe (2014-2024) was used for the selection of the articles, with peer-reviewed research articles in English language being considered for the review. As such, the large majority of articles excluded from the search were either outside the defined timeframe, duplicates, with no full-text available online, in other languages than English or irrelevant to the defined research question. No geographical limitations were set for the search purposes. And outdated definition of endometriosis used for the research was considered an exclusion criteria in the screening process of the article search.

The data collection process is illustrated using PRISMA flow chart (Page et al., 2021). The initial search results using the defined search keywords provided 318 articles. The search also helped identify a number of research articles that did not provide a direct answer to the research question but did supply a valuable context and deepened understanding of the current state of affairs for the topic at hand. There were 9 articles selected for the review, summarized in Appendix 1.

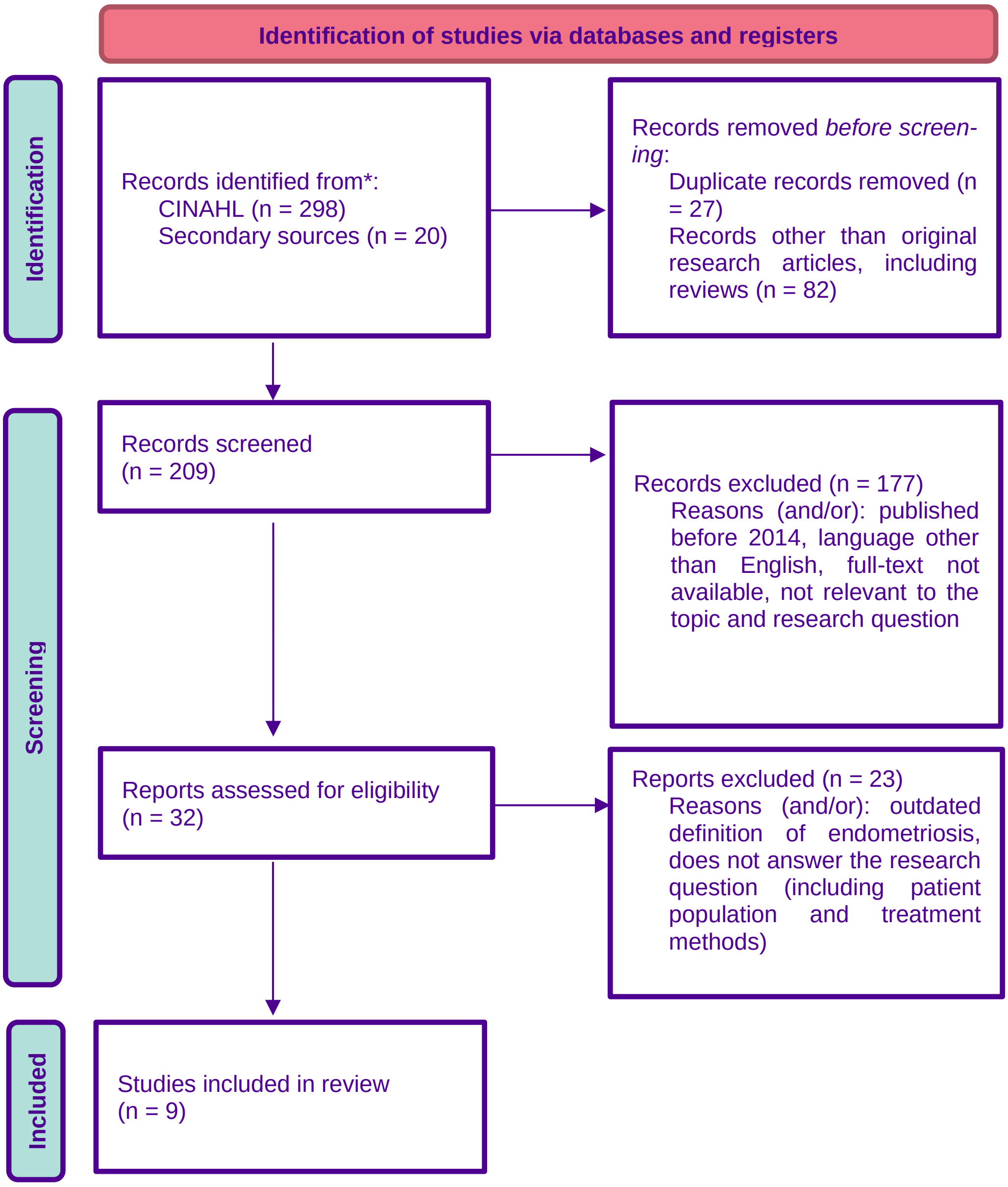

Figure 1. PRISMA chart describing the process of research article selection

5.3 Qualitative content analysis

In qualitative content analysis, findings are conveyed through categorized patterns or overarching themes (Graneheim et al., 2017). The goal of qualitative analysis is to explore, describe and understand certain phenomena that the researcher may or may not have a strong background knowledge about (Kyngäs et al., 2020, p. 5), thus shaping qualitative analysis to be more interpretive than quantitative. Qualitative content analysis is characterized by different approaches, from which the inductive approach was used in the case of this study. The inductive approach is a data-driven method that looks to identify similarities and patterns between data collected – smaller components of data are grouped to identify common themes, and broader conclusions are drawn from that (Graneheim et al., 2017). It has been noted that inductive content analysis is most often performed by one researcher, which has also been true in the case of this research, and as such, evaluating the representativeness of the data would be valuable to ensure the credibility of the results (Elo et al., 2014).

In practice, the analysis of the research at hand was started by identifying all the themes emerging from the selected articles and identifying common motives, after which only the ones applicable to the set research question were advanced towards content analysis. By doing this, it facilitated more in-depth understanding of the general context of current trends in endometriosis care, as perceived by the patients. On the other hand, this approach required returning to the results – including the final results – multiple times, thus demanding more time for analysis than anticipated and making it challenging to differentiate some of the results and whether they are applicable to the research question. Colour coding was found to be beneficial in both the original phase collection and the clustering of reductions for two reasons: this was the first time the researcher performed qualitative content analysis (Kyngäs et al., 2020, p. 14) and because of the large amount of applicable data presented in the articles. The table summarizing the themes identified in the selected articles is presented in Appendix 2.

6 RESULTS

The articles chosen for analysis were published between 2018 and 2023 and represent some of the current issues in endometriosis care in Europe (France, Sweden, Finland, Denmark and Ireland), Australia and the USA. All studies considered patient experience with some involving also health care providers' perspectives, and most of the studies identified potential areas of improvement in endometriosis care based on patient experience. While the studies pinpointed more areas of improvement than are considered in this review, only those results applicable to the research question were considered. Furthermore, it is vital to remember that nurses – within the scope of their practice – can directly influence some areas of endometriosis care, while others require more systemic change (for example, more surgeons trained in minimally invasive gynecology and endometriosis excision, or resources allocated to endometriosis research).

The content analysis of this review identified two main categories that reflect some of the main issues in endometriosis care as reported by patients, with a potential correlation to each other. Firstly, medical gaslighting continues to be reported as a prevalent communication issue, specifically in endometriosis. As an answer to this challenge, the first main category identified was '*Enhancing patient-centered care in endometriosis*'. The phenomenon of medical gaslighting seems to be directly related to the level of scientific understanding and prevalence of myths or misinformation among the patients and the healthcare providers. As such, the other area of improvement exposed in the articles analysed, was lack of awareness, information and education, leading to the other main category: '*Strengthening endometriosis education and knowledge dissemination*'.

The proposition (and potential concept for further research) is that improving the latter may in turn also improve the former, thus repairing patient experiences and reinforcing treatment, and improving public understanding of the severity and characteristics of endometriosis. In this review, however, the two are considered separately, and from the perspective of nurses being a key part of addressing these issues. The categories are summarized in Figure 2.

Enhancing patient-centered care in endometriosis

- 1. Preventing dismissal of endometriosis symptoms
- 2. Preventing gender bias and normalization of endometriosis symptoms
- 3. Considering patients' lived experience
- 4. Empathic and individually tailored communication with the patient

Strengthening endometriosis education and knowledge dissemination

- 1. Providing reliable, evidence-based information to patients
- 2. Providing recent information of high scientific quality to other health care providers with the aim to educate
- 3. Providing targeted information to specific groups (general public, young people, pregnant individuals or those hoping to conceive, those in menopause)
- 4. Following research results to maintain own up-to-date knowledge

Figure 2. Main and sub-categories identified in the content analysis.

6.1 Enhancing patient-centered care in endometriosis

For visual clarity, in the Content analysis of selected articles (Appendix 2), *Enhancing patient-centered care in endometriosis* has been referred to as ‘1’. While initially there were more sub-categories identified, results were later revisited and re-categorized into four prevalent sub-categories within the main category describing medical gaslighting. Almost all of them were consistently present in every article analysed.

Dismissal of endometriosis symptoms presented as the most common issue related to gaslighting of patients, with respondents recalling health care providers not taking patients’ symptoms seriously or neglecting them (1, 2, 2, 4, 7, 9), suggesting that their pain is psychological or stress-related (1, 2), treating patient complaints as not worthy of consideration (2, 7, 9) and being discredited or disbelieved (2, 3, 4, 5, 9). Additionally, patients reported feeling like they were not being heard or listened to (1, 2, 2, 4, 9). Mistrust in health care providers and the health care system in general emerged as a result of being let down by ignorant professionals (5, 6). In several cases the dismissal of symptoms was estimated to be closely related to the health care providers’ poor understanding of the disease and its characteristics as supported by up-to-date evidence (2, 6).

A similar, yet slightly divergent sub-category split off from the previous. While **gender bias and normalization of endometriosis symptoms** were equally common in patient experiences, they indicate symptom dismissal as happening specifically in regard to the patients’ gender and the normal (not disease-related) biological implications stemming from it (e.g. menstruation, childbearing). Patients reported health care providers normalizing suffering during menstruation (1, 2, 6, 9) and normalizing abnormal symptoms and suffering (3, 5, 6, 6) as part of the female experience in general. Pain in particular was normalized or misattributed in the context of the patients being female (5, 6, 9) and some patients reported the symptoms to be taken seriously only once endometriosis affected their ability to conceive (5, 7).

Dismissal and normalization of symptoms have been differentiated as a means of comprehensibility – while both terms may look similar on the surface, they have different dynamics and implications, especially in the context of endometriosis. Dismissal happens when a healthcare provider rejects, ignores, or minimizes a patient's symptoms outright, whereas in normalization symptoms are acknowledged but treated as typical or expected (for example, based on the patient’s gender), even when they are excessive or disruptive.

Dismissing **patients’ lived experience** and their expertise-by-experience was identified as a sub-category defined by disregarding patients’ recognition of their bodies and the holistic effect endometriosis has on their physical and mental health and wellbeing (3, 5, 5, 5, 8, 8). This includes patients’ experiences being invalidated (2, 3, 4, 6) or ignored (2, 5), despite patients displaying embodied understanding of endometriosis as not being equal to the normal condition of their bodies. A suggestion for a lower threshold of suspicion and a greater role for patients in decision-making regarding treatment based on their needs and values was made as an area of improvement (3, 3, 4, 5, 9) with a note of involving endometriosis nurses to provide an opportunity for a more holistic approach (8).

Finally, flaws in **communication** were commonly brought up in regard to gaslighting, invertedly bringing forth the consideration of a more **empathic and individually tailored communication with the patient** approach. While the competency to communicate in a patient-centered manner is already an essential skill for health providers to possess, it becomes even more important in the context of endometriosis patients which are gaslit on a regular basis. Patronizing attitudes (1, 5, 7) and a lack of empathy, compassion and consideration (1, 2, 3), as well as lacking interpersonal skills (1, 3, 8) were noted as common obstacles in facing patients. Validating patients' experiences (2, 3, 5, 6), on the other hand, had a great impact on their coping.

6.2 Strengthening endometriosis education and knowledge dissemination

For visual clarity, in the Content analysis of selected articles (Appendix 2), *Strengthening endometriosis education and knowledge dissemination* has been referred to as '2'. Similarly to the other main category, education and knowledge dissemination initially presented with more ideas than the final four sub-categories. A more detailed look is recommended for further, in-depth research.

The most common area of improvement in raising awareness as noted by the respondents, was the lack of- and the subsequent need for the patients to be able to access and be provided with **reliable, evidence-based, up-to-date information** regarding endometriosis, its characteristics, diagnosis, pathogenesis, heredity, treatment and recurrence, as well as advice on searching for trustworthy information on their own and guidance on coping, including additional therapies and life style changes that can be adopted in attempt to improve the quality of life. Patients reported an increased need for general information about the disease, its characteristics and all available treatments and options (1, 3, 4, 7, 7, 8, 9, 9) that needs to be supplied in a proactive and clear manner (1, 3). Focus was placed on the information to be of high scientific quality, reliable and up-to-date (which overlapped with the need for the information provider to follow research and thus keep their own knowledge at a high standard) (4,7). As such, the information provider would also be able to equip the patients with the tools to educate and locate reliable information themselves (7, 8, 9). The role of endometriosis nurses and the potential of their expertise was emphasized regarding this subcategory in one study (8).

The need to provide **information to other health care providers**, who might have outdated knowledge about endometriosis, was mentioned almost as often as the need of information provided to patients. Lack of competence was reported, and it was assessed by patients to be closely related to the dismissal of and inability to recognize endometriosis symptoms (2, 2, 6), poor understanding of diagnosis and treatment (2, 6, 9), and being unaware of evidence-based treatment – propagating outdated views based in medical myths (2, 2, 3, 5). The plea for increased endometriosis education for health care providers emerged from patients' responses as a result (4, 5, 6, 7). In some cases, the lack of health care providers' competence was directly related to decline in patients' mental health and personal relationships (6, 9).

While less prominent, the **need for information provided to specific groups** also emerged as an area of concern among patient responses. This included information provided to public as part of raising awareness about the disease (1, 9), information to women entering or in menopause (7), information to those considering pregnancy and patients with infertility (5, 7, 7), information regarding counselling and education of family members, friends and colleagues (7, 9) and information for young people (7, 9).

Following research results (2, 4, 5, 7) surfaced as a separate unmet need when mentioned as leading to a lack of recent, evidence-based information for patients and a lack of competence in up-to-date approaches in professional practice.

7 DISCUSSION

While the results of this review indicate severe lack of knowledge and awareness in society, as well as unmet needs in endometriosis care closely related to the lack of evidence-based approach in managing the disease, it does conversely offer clear proposal of improvements that could be supported by introducing more nursing professionals to endometriosis care. The ICN position statement of scope of nursing practice (ICN, 2010) formulates that the scope of nursing practice is dynamic and extends beyond limited set of functions, instead authorizing and enabling nurses to integrate their knowledge with educational and research responsibilities, and patient advocacy. As such, regardless of what the local characteristics of nurses’ functions are in each country, most of the unmet needs brought up in this review can indeed be addressed – in one way or another – by nurses.

On a broader level, nurses working in general practice, health centres and schools should as a minimum be able to recognize suspected endometriosis symptoms in all age groups (not only reproductive age) and have trustworthy knowledge of where to refer such patients if specialist level care is needed in diagnosis and management of their disease. If symptoms are under control and general care is deemed enough for the patient, they should also be able to provide (or know how to locate) reliable information on managing the condition in a holistic manner, including lifestyle choices and effect on mental health and coping. Nurses working in closer connection to female patients (gynecology in- and outpatient care, midwifery and prenatal care, sexual health, endometriosis centres – where such exist – and nurse specialists with an expertise related to endometriosis), as well as those working in fields where endometriosis symptoms are commonplace (gastroenterology, particularly of the lower GI tract, and urology) should, in addition, be familiar with recent noteworthy research findings applicable to their practice needs, and be able to disseminate such information to both, their colleagues and patients.

The findings of this review suggest that the role of nurses in endometriosis care could be one of building a “bridge” between the patient and the endometriosis specialist. Since endometriosis care is currently characterised by persistent prevalence of outdated knowledge, medical myths, gender bias and lack of menstrual education, raising awareness and disseminating information that is based on high quality research is among the most important tools – and the most available in terms of resources – to improve the care provided. Defining best care pathways, promoting early detection, optimizing the focus of endometriosis research, embracing evidence-based approaches, and reinforcing effective multidisciplinary care are all steps that have been called for improvement (Guidone, 2020) and can be facilitated by application of nursing expertise, as demonstrated in other countries' examples (Armour et al., 2022).

A large systematic issue could be addressed by taking the patient's lived experience into consideration already from the initial contact, as considering patients' holistic needs us something that particularly nurses are trained for. While it may seem counterintuitive, people affected by endometriosis are often highly knowledgeable and can serve as an invaluable educational resource, particularly when encouraged to share their insights and personal experiences with the condition (Australian College of Nursing, 2021). By regarding these insights with attention and reflection, it would not just enable the professional to provide a holistic approach (which is necessary not only for symptom management, but also improving the patient's quality of life), but also gain a deeper understanding of patterns and correlations in endometriosis – a more complex picture of what can be 'normal' in endometriosis.

More attention should be paid to training nurses in research literacy and the application of it to their practice, and resources, such as time and access (Pitsillidou et al., 2021; Hines et al., 2022), should be allocated to enable nurses to familiarise themselves with recent research results relevant to their field. A deeper scientific understanding of the condition encountered and approaching the patient from a holistic perspective might as well help improve the attitudes as endometriosis is still found to be a deeply gendered condition, also among nurses, and as such endometriosis patients' suffering tends to be psychologized and the blame of being ill assigned to the patients (Bach et al., 2016). In a disease as common as asthma or diabetes, but damaged by much larger societal and professional ignorance (Hudson, 2021), patients' situation begs for prompt changes.

8 ETHICS AND RELIABILITY

The study was conducted responsibly, with respect and accountability towards the research subjects, and the results were recorded and published in alignment with The Finnish Code of Conduct for Research Integrity and Procedures for Handling Alleged Violations of Research Integrity in Finland (TENK, 2023) as committed to by Tampere Universities. Plagiarism was avoided by thorough referencing of the cited authors and keeping track of the original sources.

The potential reliability of this study may be affected by conducting it alone and being personally involved in the subject matter as a patient and a representative of the Endometriosis Association of Latvia, a patient advocacy organization. This issue was addressed by seeking peer support and advice from the thesis supervisor whenever necessary, both regarding the topic and the type of the selected research method. Original sources of research were respected and appraised critically by using the Johns Hopkins nursing evidence-based practice Research Evidence Appraisal Tool for qualitative research studies (Dang et al., 2022).

Limitations include the scope of bachelor's thesis that restricted the depth of both theoretical and research part of the review (in this regard future research of wider scope can be suggested to expand the topic), as well as the limited amount of information available about the current involvement of nurses in endometriosis care. Another possible limitation of the research is that the selected articles only represent the situation in high-income countries in Europe, The United States of America and Australia, and further research is needed to apprise the global circumstances.

9 CONCLUSION

Endometriosis is a complex disease with effects that extend far beyond reproductive health. This means there is a need for more than a gynecologist in effective management of endometriosis. Navigating the numerous aspects of a complex, chronic disease is challenging when there is an abundance of contradictory information and access to holistic care varies depending on multiple factors. This thesis sought to explore gaps in endometriosis care, particularly in patient-specialist interactions, that could be improved by increasing involvement of nurses.

The identified areas of improvement include minimizing medical gaslighting – a prevalent issue in patients' experiences – and maximizing awareness and information dissemination through patient-centred communication and the provision of reliable, evidence-based knowledge.

The author earnestly implores the reader to consider that knowledge is not exclusively reserved for diploma holders, and much of what can be learned and understood about a medical condition comes from those who experience it firsthand – if we only listen and believe. Patients' lived experience is usually taken into account in the management of most other medical conditions concerning people across the demographic spectrum, because a patient carries their embodied knowledge regardless of their social and biological identity. Why should this not also apply to those suffering from a so-called "women's disease"?

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APPENDICES

Appendix 1. Summary of selected articles

Authors, year, country, title	**Purpose**	**Sample and methods**	**Key results**
1. Gouesbet, Solène; Kvaskoff, Marina; Riveros, Carolina; Diard, Élise; Pane, Isabelle; Goussé-Breton, Zélia; Valenti, Michelle; Gabillet, Marie; Garoche, Camille; Ravaud, Philippe; Tran, Viet-Thi. 2023. France, USA. Patients' Perspectives on How to Improve Endometriosis Care: A Large Qualitative Study Within the ComPaRe-Endometriosis e-Cohort	To capture ideas to improve endometriosis care from the patients' perspectives.	Cross-sectional data analyzed from 1,000 adult patients in a French prospective e-cohort focused on endometriosis. The respondents answered an open-ended question, and their responses were analyzed by qualitative thematic analysis using an inductive approach.	The top 5 areas of improvement: train caregivers to develop their knowledge on the disease, provide better management of daily pain and pain attacks, take patient reported symptoms seriously, standardize diagnostic processes to improve early detection, and have caregivers listen more to the patients.
2. Mikesell, Lisa; Bontempo, Allyson C. 2023. USA. Healthcare Providers' Impact on the Care Experiences of Patients with Endometriosis - The Value of Trust	To examine the relationship between patients' experiences with endometriosis and misdiagnosis and use of patient online communities.	Participants included 997 adult patients representing 38 countries. The data analysed and presented in the manuscript stem from an open-ended question included in a survey. Analytical procedures were initially inductive and involved several steps using thematic analysis with a second, deductive phase of coding.	The results identified barriers and limitations related to health care providers' impact on the endometriosis patients' care experiences, including 'health care providers as barriers to care' and 'health care providers as facilitators to care'.
3. Rowe, Heather J; Hammarberg, Karin; Dwyer, Sarah; Camilleri, Renea; Fisher, Jane. 2021. Australia. Improving clinical care for women with endometriosis: qualitative analysis of women's and health professionals' views	To compare women's and health professionals' perceptions of quality of endometriosis health care and opportunities for improvements.	46 women, 12 general practitioners (GPs), and 1 gynecologist participated. Women participated in closed moderated online discussion groups and health professionals in semi-structured telephone interviews. Discussion group text and interview transcripts were thematically analysed using the Framework Analysis approach.	Women reported that health care providers may dismiss symptoms, lack essential knowledge and provide inconsistent advice; treatments are seldom successful or without adverse side-effects. Health professionals acknowledged limitations in expertise, persistent myths, and challenges in achieving best practice.
4. Omtvedt, Marianne; Bean, Elisabeth; Hald, Kirsten; Larby, Elisabeth Raasholm; Majak, Guri	To establish what the users' perspectives are on best possible care in the context of	A questionnaire was developed in collaboration between the Norwegian Patient's	Better patient information, long-term therapeutic plans and integration of their partners into their

B.; Tellum, Tina. 2022. Norway, UK. Patients' and relatives' perspectives on best possible care in the context of developing a multidisciplinary center for endometriosis and adenomyosis: findings from a national survey	developing a multi-disciplinary center for endometriosis and adenomyosis in Norway.	Endometriosis Society and gynecologists with interest in endometriosis and adenomyosis. 938 participants answered the questionnaire. Qualitative analysis was used to evaluate the answers.	care were the main concerns. Multidisciplinary care was a key issue for the majority, and the majority considered research and quality assurance initiated by the endometriosis centre to be important.
5. Evans, Subhadra; Villegas, Valeria; Dowding, Charlotte; Druitt, Marilla; O’Hara, Rebecca; Mikocka-Walus, Antonina. 2022. Australia. Treatment use and satisfaction in Australian women with endometriosis: a mixed-methods study	To document the frequency of conventional and complementary treatments used by Australian women with endometriosis and the perceived efficacy of these treatments, and to qualitatively explore women’s treatment satisfaction.	Using a mixed-methods design, 532 women with self-reported endometriosis were recruited from the community. Participants were asked about their medication, complementary and self-care treatment use, as well as perceived efficacy on a 0 to 10 numeric rating scale, and open-ended qualitative survey items about treatment satisfaction.	Content analysis of the qualitative data identified women’s level of satisfaction with treatment. The analysis identified qualitative themes relating to barriers to treatment, which included lack of access, stigma and disappointment with medical professionals who were perceived as uncaring, unhelpful and, in some cases, psychologically damaging; the need for holistic, interdisciplinary care; and patient knowledge, advocacy and resilience in endometriosis management.
6. Grundström, Hanna; Alehagen, Siw; Kjølhede, Preben; Berterö, Carina. 2018. Sweden. The double-edged experience of health care encounters among women with endometriosis: A qualitative study	To identify and describe the experience of health care encounters among women with endometriosis.	A qualitative, interpretive, phenomenological approach was used. 9 women aged 23–55, with a laparoscopy-confirmed diagnosis of endometriosis were interviewed. The interviews were recorded and transcribed verbatim. The data was analysed following the steps of the interpretive phenomenological approach.	Two themes were identified in the interview transcripts: being treated with ignorance and being acknowledged. The essence: “the double-edged experience of health care encounters” emerged from the themes. The women’s experience was double-edged as it involved contradictory feelings: the encounters were experienced as both destructive or constructive.
7. Remes, Anna; Hakala, Mervi; Oikarinen, Anne. 2023. Finland. Endometriosis patients’ experiences of the counselling they need from the nurses through the digital care pathway: A	To describe endometriosis patients’ experiences of the counselling they need from the nurses through the digital care pathway.	A qualitative descriptive study was conducted; 14 Finnish women with endometriosis were interviewed.	Content analysis revealed 4 main categories related to counselling provided through the digital care pathway: counselling on endometriosis and its role in life;

qualitative descriptive study			counselling on how to live with endometriosis; comprehensive support for self-care; and patient-oriented counselling.
8. Simonsen, Susan Munch; Strømberg, Charlotte; Zoffmann, Vibeke; Hartwell, Dorte; Olesen, Mette Linnet. 2020. Denmark. About me as a person not only the disease – piloting Guided Self-Determination in an outpatient endometriosis setting	To assess the implementation of the Guided Self-Determination method targeted women with complex endometriosis appeared feasible and supported self-management.	Guided Self-Determination was offered to 10 outpatients with complex endometriosis. Each participant had five conversations based on pre-filled disease specific reflection sheets. A qualitative evaluation was conducted covering semi-structured, telephone interviews and focus group interviews, which were analysed using thematic analysis.	4 themes were identified: feeling alone with the disease; establishing a meaningful relationship with health care professionals in a traditional hospital setting; person-specific knowledge facilitated new behaviors and accepting a chronic condition – the beginning of a process.
9. Lightbourne, Ayisha; Foley, Sarah; Dempsey, Maria; Cronin, Mary. 2023. Ireland. Living With Endometriosis: A Reflexive Thematic Analysis Examining Women's Experiences with the Irish health care Services	To explore the perceptions and experiences of women with endometriosis regarding the diagnosis, support and treatment options available in Ireland.	20 participants, women aged 18 and over with a diagnosis of endometriosis and experience of the Irish health care system, were recruited through purposeful sampling to complete semi-structured, one-to-one online interviews. Data was analysed using reflexive thematic analysis.	5 themes were identified: dismissive attitudes normalizing severe pain, inadequate health system, the impact of delayed diagnoses, lack of education and awareness and navigating ignorance, taboo and societal views.

Appendix 2. Content analysis of selected articles

Original phrase	Reduction	Sub-category	Main category
Improving caregivers' knowledge and recognition of the disease. This theme included 5 areas of improvement with a total of 414 ideas related to 1) better training caregivers on the disease, 2) providing more explanation about the disease to patients, 3) having the disease better recognized by doctors, 4) stop believing that it is normal to suffer during menstruation, and 5) developing research on endometriosis. (1)	providing (more) explanation about the disease to patients (1) stop believing that it is normal to suffer during menstruation (1)	reliable, evidence-based information to patients preventing gender bias and normalization of symptoms	2 1
Stopping medical violence. This theme contained 7 areas of improvement with a total of 256 ideas related to 1) taking patient-reported symptoms seriously, 2) stopping telling patients that their pain is psychological or stress-related, 3) not judging patients, 4) stopping patronizing patients, 5) ending gender-biased care, 6) ensuring that there is no more physical and emotional abuse in care, and 7) guaranteeing patient intimacy (1)	taking patient-reported symptoms seriously (1) not telling patients that their pain is psychological or stress-related (1) not patronizing patients (1) ending gender-biased care (1)	preventing dismissal of symptoms preventing dismissal of symptoms empathic, individual communication preventing gender bias and normalization of symptoms	1 1 1 1
Improving some qualities of caregivers. This theme included 4 areas of improvement with a total of 230 ideas related to 1) making caregivers listen to patients, 2) increasing their empathy towards patients, 3) making them more proactive in providing information, initiating follow-up and monitoring, and 4) training them in interpersonal skills. (1)	listening to patients (1) increasing empathy towards patients (1) being proactive in providing information (1)	preventing dismissal of symptoms empathic, individual communication reliable, evidence-based information to patients	1 1 2

	improving interpersonal skills by training (1)	empathic, individual communication	1
Improving society's awareness and recognition of disease. This theme included 4 areas of improvement with a total of 132 ideas related to 1) improving the public recognition of the disease, 2) recognizing endometriosis as a chronic disease, a long-term disabling condition, or a disability by the social security administration, 3) raising awareness among the general public, and 4) providing more information on research results. (1)	improving the public recognition of the disease/raising awareness among the general public (1) providing information on research results (1)	information to specific groups following research results	2 2
Although occurring less frequently (38 comments), respondents also described a causal relationship between competence and fidelity, whereby a lack of competence on the part of the health care provider was perceived to lead the health care provider to dismiss or neglect the patient's symptoms. (2)	a lack of competence on the part of the health care provider was perceived to lead to dismission or neglect of the patient's symptoms (2)	information to health care providers AND preventing dismissal of symptoms	2 AND 1
For instance, when raising concerns, participants described health care providers as "incompetent", "unskilled", and "unknowledgeable". However, respondents' comments just as often described incompetence as it related specifically to health care providers' poor understanding of diagnosis and/or treatment. (2)	health care providers' incompetence connected to their poor understanding of diagnosis and/or treatment (2)	information to health care providers	2
Regarding diagnosis, respondents described health care providers' inability to recognize symptoms and recommend appropriate testing. (2)	health care providers' inability to recognize symptoms (2)	information to health care providers	2
Regarding treatment, respondents lamented that health care providers were unaware of evidence-based treatment options and often recommend outdated, extreme, or unrealistic treatments such as hysterectomy for a female of childbearing age who wanted children or getting pregnant for a teenager still in high school (both instances were reported). (2)	health care providers being unaware of evidence-based treatment options (2) recommendations of outdated, extreme, or unrealistic treatments such as hysterectomy or getting pregnant (2)	information to health care providers information to health care providers AND following research results	2 2
Concerns regarding fidelity highlighted experiences in which patients felt their symptoms and experiences were "normalized",	symptoms being normalized, minimized, ignored and dismissed (2)	preventing gender bias and normalization of symptoms	1

"minimized", "ignored" and "dismissed". Many respondents also reported feeling that they were in turn "invalidated", "dismissed", "ignored", or "disbelieved". In these comments, health care providers were described as "insensitive", "uncaring", "inconsiderate", "rude", and "hurtful". (2)	patients’ experiences being invalidated, dismissed, ignored or disbelieved (2)	considering lived experience	1
	health care providers being insensitive, uncaring, inconsiderate, rude and hurtful (2)	empathic, individual communication	1
Patients commonly described feeling not heard and not taken seriously as consistent breaches of fidelity. (2)	feeling not heard (2)	preventing dismissal of symptoms	1
	not being taken seriously (2)	preventing dismissal of symptoms	1
When recounting concerns about feeling discounted, some respondents remarked how it was nonsensical for health care providers to ignore patients who know their bodies best. (2)	it was remarked as nonsensical for health care providers to ignore patients who know their bodies best (2)	considering lived experience	1
Similarly, other respondents remarked on how health care providers normalized and dismissed symptoms that patients knew to be abnormal and requiring medical attention. (2)	health care providers normalizing and dismissing symptoms that patients knew to be abnormal (2)	preventing gender bias and normalization of symptoms	1
This lack of fidelity that patients experienced, feeling unheard and discredited, was described as commonplace, occurring across many visits involving many health care providers. Most respondents identified experiences in which health care providers systematically did not recognize or treat their symptoms and experiences as worthy of care or consideration, leaving them to feel dismissed, unsupported, in a heightened state of vulnerability and, as several patients described, like "they were the crazy ones". (2)	feeling unheard and discredited was described as commonplace (2)	preventing dismissal of symptoms	1
	experiences in which health care providers systematically did not recognize or treat patients’ symptoms as worthy of care or consideration (2)	preventing dismissal of symptoms	1
	systematic dismission by health care providers (2)	preventing dismissal of symptoms	1
Respondents perceived that health care providers' poor understanding of endometriosis was what led them to be dismissive. (2)	health care providers' poor understanding of endometriosis connected to them being dismissive towards patients (2)	information to health care providers AND preventing dismissal of symptoms	2 AND 1
Patients also recognized the value of fidelity - when health care providers attended to their socioemotional needs and validated their experiences - even from "incompetent" health care providers. (2)	the value of health care providers attending to patients’ socioemotional needs and validating their experiences even when they were not specialists in endometriosis (2)	empathic, individual communication	1

Symptoms may be disbelieved, and the pursuit of satisfactory treatments consumes considerable energy and resources. (3)	disbelief of patients’ symptoms (3)	preventing dismissal of symptoms	1
Women confirmed the need for reliable information about endometriosis and available treatments. However, this need can be poorly met, leading to help-seeking from a variety of other sources. (3)	the need for reliable information about endometriosis and available treatments (3)	reliable, evidence-based information to patients	2
Mentally and physically painful symptoms demand compassionate care, which women and health professionals agreed can be inadequate. (3)	both patients and health care providers agreed that endometriosis demands compassionate care, but it can be inadequate (3)	empathic, individual communication	1
First, health professionals recommended improving physicians' knowledge of menstruation, its pathologies and when to refer for specialist investigation and treatment. A low threshold of suspicion of endometriosis may assist, balancing a priority for early referral with potentially pathologizing normality. Enhanced understanding of endometriosis from a broader psychosocial perspective was also advocated. (3)	health care providers advocated improving knowledge regarding women's health and illness (3) health care providers advocated a low threshold of suspicion of endometriosis (3) health care providers advocated enhanced understanding of endometriosis from a psychosocial perspective (3)	information to health care providers considering lived experience considering lived experience	2 1 1
There were also strongly expressed needs for women's expertise to be utilized, for women to be accorded more agency and a greater role in decision-making. (3)	the need for patient expertise to be utilized and their opinions to have a greater role in decision-making (3)	considering lived experience	1
Health professionals' recommendations were first to listen to women’s concerns and values and discuss them with empathy and respect. Second, to give clear explanations of the available options and third, offer shared decision-making. (3)	health care providers recommended to listen to women’s concerns and values and discuss them with empathy and respect (3) health care providers recommended giving clear explanations of the available options (3) health care providers recommended offering patients shared decision-making (3)	considering lived experience AND empathic, individual communication reliable, evidence-based information to patients considering lived experience	1 2 1
In an open-ended question, the participants were asked about their thoughts on how they can best be involved in a joint treatment decision. The participants (n=497) emphasized the importance of their values, preferences and needs being respected,	participants emphasized the importance of their values, preferences and needs being respected (4)	considering lived experience	1

and the importance of knowledgeable health care takers providing them balanced information about endometriosis and adenomyosis, so that they can make a shared decision about treatment. (4)	participants emphasized the importance of knowledgeable health care providers in terms of endometriosis (4)	information to health care providers	2
	participants emphasized the importance of health care providers providing balanced information about endometriosis (4)	reliable, evidence-based information to patients	2
	participants emphasized the importance of a shared decision making about treatment (4)	considering lived experience	1
Most patients also reported that they did not perceive being taken seriously/believed in/listened to/understood in their dialogue with health care professionals. (4)	participants reported not being taken seriously and believed in by health care professionals (4)	preventing dismissal of symptoms	1
	participants reported not being listened to by health care professionals (4)	preventing dismissal of symptoms	1
In this open-ended question, the participants answering (n=614) repeated many previously mentioned needs, such as up to date information, a high competence level among the health care professionals in charge, follow-up and multidisciplinary care. (4)	an unmet need for up-to-date information was indicated (4)	reliable, evidence-based information to patients AND following research results	2
The strongest message was a sense of being let down by medical staff. Women felt they were being perceived as 'crazy', and that their pain did not matter or exist: "It's not just in my head". (5)	being let down or disbelieved in by medical staff (5)	preventing dismissal of symptoms	1
	patients' pain considered as not mattering or not existing (5)	preventing gender bias and normalization of symptoms	1
Participants reported medical gaslighting, where doctors led them to believe menstrual pain was normal, and that women could not experience as much pain as they were claiming. (5)	respondents reported medical gaslighting where they were led to believe their pain was normal or not as strong as they were claiming (5)	preventing gender bias and normalization of symptoms	1
Medical myths were common, including being misinformed that having a baby would cure endometriosis. (5)	medical myths from health professionals regarding endometriosis (5)	information to health care providers AND following research results	2
Many women reported that they were finally satisfied, long journey of moving from one unhelpful doctor to another, until finding a medical professional who listened and had adequate knowledge and training about endometriosis. (5)	long attempts to find a medical professional who listened (5)	considering lived experience	1

	long attempts to find a medical professional who was knowledgeable about endometriosis (5)	information to health care providers	2
Of endometriosis symptoms, infertility was typically treated with the most time and validation. Many women only received a diagnosis of endometriosis when trying unsuccessfully to conceive, even though they had experienced unaddressed symptoms for years. (5)	respondents reported only receiving diagnosis of endometriosis when trying unsuccessfully to conceive, despite a long history of other unaddressed symptoms (5)	preventing gender bias and normalization of symptoms	1
Pain was also taken seriously by some doctors, but to a lesser extent. (5)	compared to infertility, pain is also taken seriously as a symptom, but to a lesser extent (5)	preventing gender bias and normalization of symptoms	1
Other common and disabling symptoms, such as fatigue, and disruptions to mental health and QoL were largely unaddressed, leading women to call for a more holistic approach to endometriosis care. (5)	fatigue is reported to be largely unaddressed (5) disruptions to mental health are reported to be largely unaddressed (5) disruptions to quality of life are reported to be largely unaddressed (5)	considering lived experience considering lived experience considering lived experience	1 1 1
Women also noted they needed to trust their own bodies and intuition when trying novel treatments. (5)	respondents noted the importance of trusting their own bodies when trying novel treatments (5)	considering lived experience	1
Rather than talking about being cured by treatment, women described learning to accept and live with endometriosis. There was a need to remain 'positive', 'strong' and 'persistent' in pursuing a fulfilling life while searching for adequate care: "You have to learn to live with it and continue your daily activities as much as possible". Even for the women who noted the importance of remaining positive and using acceptance, non-judgmental expert care was considered essential. (5)	even for the respondents who noted the importance of resilience, non-judgmental care was found to be essential (5)	empathic, individual communication	1
Looking back at their experience of healthcare encounters, the women described a long struggle characterized by ignorance, that is, exposure, disbelief and lack of knowledge. (6)	respondents' health care encounters were described as a long struggle characterized by ignorance (6)	preventing dismissal of symptoms AND information to health care providers	1 AND 2
The women often encountered the attitude that they exaggerated or imagined their symptoms or had low pain thresholds. (6)	encountering the attitude that they (patients) exaggerated or imagined their symptoms (6)	preventing gender bias and normalization of symptoms	1

	encountering the attitude that they have low pain thresholds (6)	considering lived experience	1
In the pre-diagnosis encounters, health care providers were focused on finding an "easy explanation", for example, infections, miscarriage or irritable bowel syndrome. When the symptoms did not disappear, the health care providers resorted to normalizing and trivializing the problems. (6)	health care providers were reported to be focusing on easier explanations for their symptoms (6)	preventing gender bias and normalization of symptoms	1
	health care providers were reported to be normalizing the symptoms when the explanation did not prove to be right (6)	preventing gender bias and normalization of symptoms	1
Sometimes the women experienced that the health care providers lacked basic knowledge about endometriosis. (6)	patients experienced health care providers lacking basic knowledge about endometriosis (6)	information to health care providers	2
Women noticed that good people skills often went hand in hand with a good pedagogic ability. Health care providers who could convey useful information and knowledge could change women's lives. (6)	health care providers with people skills and the ability to convey information were considered life-changing (6)	empathic, individual communication	1
It was destructive to encounter health care providers who lacked knowledge and who dismissed the "hidden" symptoms as part of normal female life, considering menstrual pain as "bad luck" rather than a sign of a potentially serious disease. (6)	encountering health care providers who lacked knowledge was reported to be destructive (6)	information to health care providers	2
	encountering health care providers who were dismissive and who normalized pain was reported to be destructive (6)	preventing gender bias and normalization of symptoms	1
Participants highlighted the need for information on endometriosis, i.e. what it means as a disease, what is the pathogenesis of endometriosis, and whether it can recur. The participants showed interest about the prevalence and heredity of endometriosis, as well as how endometriosis affects other diseases. (7)	being able to receive in-depth information about endometriosis, its pathogenesis, heredity and recurrence was noted as important (7)	reliable, evidence-based information to patients	2
Some participants in the older age group felt that there is limited information about endometriosis after menopause available on the Internet. (7)	limited availability of information regarding endometriosis after menopause was reported (7)	information to specific groups	2
Moreover, the participants felt that it was important to point out what is so-called "normal" and what is not in endometriosis, i.e. information available on the digital care pathway could emphasize that severe menstrual cramps are not a part of normal life. (7)	the importance of knowing what is normal and what is not regarding endometriosis was noted (7)	reliable, evidence-based information to patients	2

A need for information on how endometriosis affects reproductive health was also identified from the interviews, with a particular emphasis on how the disease affects infertility. The participants felt that issues related to infertility should be reported as gently as possible. In addition, participants felt that counseling concerning the effects of endometriosis on pregnancy, along with information on pregnancy-related issues after endometriosis surgery, would be of value. (7)	a need for information about how endometriosis affects fertility and pregnancy was expressed (7)	information to specific groups	2
	counseling about the effects of endometriosis on pregnancy would be of value (7)	information to specific groups	2
	information on pregnancy-related issues after endometriosis surgery would be of value (7)	information to specific groups	2
Participants had a difficult time talking about the disease in different situations. As such, they felt that they needed more counseling on how to speak about their disease to loved ones, work colleagues, and friends; this was emphasized because the disease has such a great impact on women's daily lives. Some participants felt that it would be important for their spouse to be educated about the disease via the digital care pathway. (7)	a need for counseling on how to talk about their disease to loved ones, colleagues and friends (7)	information to specific groups	2
	a need for education on endometriosis for their spouses (7)	information to specific groups	2
The participants highlighted that information provided via the digital care pathway should be reliable and evidence-based. This means that the information provided should be reliable, relatively recent, and of high scientific quality. Participants also wanted advice on how to find reliable information. (7)	participants wanted the information to be reliable, recent and of high scientific quality - evidence-based (7)	reliable, evidence-based information to patients AND following research results	2
	participants wanted advice on how to find reliable information themselves (7)	reliable, evidence-based information to patients	2
The participants also hoped that awareness of the disease would be increased among both professionals and young people. Professionals working with endometriosis patients should be knowledgeable and specialized in the treatment of endometriosis as such, the participants shared that they expected the professionals to be understanding and humane towards patients, symptoms should be addressed and pain should never be underestimated. (7)	a need for increased awareness among professionals (7)	information to health care providers	2
	a need for increased awareness among young people (7)	information to specific groups	2
	a need for endometriosis professionals to have a humane attitude towards patients (7)	empathic, individual communication	1
	participants expressed that pain should never be underestimated (7)	preventing dismissal of symptoms	1

They pointed out that these conversations were focused on their personal needs and preferences. They experienced it was an advantage that the nurses had both communicative competences, disease-specific knowledge and time for conversations was prioritized. (8)	participants appreciated conversations being focused on their personal needs and preferences (8)	considering lived experience	1
	participants expressed it is an advantage that an endometriosis nurse has communicative competences (8)	empathic, individual communication	1
	participants expressed it is an advantage that an endometriosis nurse has disease-specific knowledge (8)	reliable, evidence-based information to patients	2
	participants expressed it is an advantage that time for conversations is prioritized with an endometriosis nurse (8)	considering lived experience	1
They experienced that the GSD-endo conversations had a positive focus on what they could do to manage the disease themselves. (8)	participants experienced the conversation with endometriosis nurse to have a positive focus on what the patient can manage self-care of endometriosis (8)	reliable, evidence-based information to patients	2
They appreciated the focus on their whole life situation with endometriosis. (8)	participants appreciated a holistic outlook on their life with endometriosis (8)	considering lived experience	1
The women gained new disease-specific knowledge about endometriosis, treatment and symptoms as well as personal knowledge about themselves and their way of managing endometriosis in daily life. (8)	participants gained new knowledge about endometriosis, treatment and symptoms during the nurse-led conversation (8)	reliable, evidence-based information to patients	2
	participants gained new knowledge about themselves and their way of managing endometriosis in daily life during the nurse-led conversation (8)	reliable, evidence-based information to patients	2
Dismissive attitudes were identified through the participants' narratives of their interactions with healthcare professionals. This included not feeling listened to, or taken seriously, when communicating their concerns about their symptoms. (9)	dismissive attitudes from health care professionals (9)	preventing dismissal of symptoms	1
	health care professionals not listening to patients (9)	preventing dismissal of symptoms	1

	health care professionals not taking patients' complaints seriously (9)	preventing gender bias and normalization of symptoms	1
Unfortunately, this normalization of severe pain permeated our data. Participants described how their painful symptomatology was not acknowledged, and debilitating menstruation was normalized in health care encounters. (9)	patients’ pain not being acknowledged (9) debilitating menstruation pain being normalized (9)	preventing dismissal of symptoms preventing gender bias and normalization of symptoms	1 1
Feeling dismissed by health care professionals became a barrier for many participants to seek further treatment. (9)	feeling dismissed by health care providers was a barrier to seeking further treatment (9)	considering lived experience	1
The lack of education and awareness in Ireland surrounding endometriosis and endometriosis care unfolded through the participants' narratives in relation to both healthcare professionals and women themselves. (9)	lack of education and awareness surrounding endometriosis in relation to health care providers (9) lack of education and awareness surrounding endometriosis in relation to patients themselves (9)	information to health care providers reliable, evidence-based information to patients	2 2
Other participants focused on the necessity to educate themselves about endometriosis and believed they had not received support or information from medical professionals on how to best manage symptoms and pain. (9)	participants noted the necessity to educate themselves about endometriosis (9) participants had not received information from medical professionals on how to best manage symptoms, including pain (9)	reliable, evidence-based information for patients reliable, evidence-based information to patients	2 2
Participants identified the impact that lack of awareness and understanding had on their relationships with family, friends and colleagues, who were unable to understand and therefore support their efforts to seek appropriate care. (9)	the lack of awareness and understanding of endometriosis had an impact on patients' relationships with family, friends and colleagues (9)	information to specific groups	2
Beyond taboo, there was a sense that the lack of specialist care and diagnosis opportunities meant pain was normalized by family and peers and therefore diminished. There was frustration that endometriosis pain was equated to regular experiences of periods and therefore deemed tolerable. (9)	pain was normalized and therefore diminished by family and peers as a result of the lack of specialist care and diagnosis opportunities (9) endometriosis pain was equated to regular periods and therefore deemed tolerable (9)	information to health care providers AND information to specific groups preventing gender bias and normalization of symptoms	2
In response, participants called for more input in schools to educate everyone on endometriosis and, especially, to ensure young girls are aware of the symptoms. (9)	participants called for more input to education in schools to raise awareness of the symptoms (9)	information to specific groups	2