# More Than Painful Periods: South Asian Women's Experiences of Endometriosis in the UK

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# Abstract

**Background:** Endometriosis is an inflammatory condition that affects 5-10% of women and those assigned female at birth. Symptoms can be chronic, yet diagnosis takes on average between 4 to 7 years. Whilst qualitative literature has begun to explore the lived experiences of women with endometriosis, there remains limited empirical explorations of the experiences of women from racialised backgrounds.

**Methodology:** This study adopted a narrative analysis approach, specifically using thematic narrative analysis to explore how 14 women from South Asian backgrounds within the UK made sense of their experiences of receiving a diagnosis and living with endometriosis. The study was grounded in critical realism, whilst also adopting a Post-Colonial Feminist approach.

**Findings:** Six narrative themes emerged: (1) Early pain, confusion, and the normalisation of suffering; (2) Limited clinician knowledge, self-advocacy, and navigating the healthcare system; (3) Diagnosis as validation, and "now what?" (4) Endometriosis as a whole-life condition and an "invisible disease"; (5) Cultural silence, shame, ignorance, and learned restraint in speaking; and (6) Resilience, growth, and strength. Overall, the findings illustrate how multiple aspects of participants' lives intersected to shape their experiences of endometriosis.

**Implications:** This study provides a novel perspective on the experiences of South Asian women, illuminating not only what they encounter but also the underlying factors shaping these experiences. The findings underscore the importance of increased investment in women's health and highlight the need to strengthen cultural competence within the NHS.

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# Chapter One: Introduction

## Chapter Overview

This chapter introduces the central focus of the thesis: An Exploration of South Asian Women's Experiences of Endometriosis in the United Kingdom. It situates the study within broader conversations about women's health, health inequalities, and intersectional feminism, establishing the conceptual and contextual foundations for the research.

The chapter begins by outlining key terms and definitions used throughout the thesis. This includes clarification of how "South Asian" is conceptualised, the meaning of "women" within the scope of the study, and discussions around the use of the term "racialised". Defining these terms is essential to acknowledge the complexity of identity, ethnicity, gender, and migration, and to ensure conceptual clarity.

The chapter then establishes endometriosis within the broader landscape of women's health, examining policy and practice in the UK alongside the historical and ongoing influence of feminist movements on women's healthcare. It then introduces endometriosis and explores the current understanding of the condition, including outlining current medical understandings of its symptoms, prevalence, diagnostic pathways, and treatment options, drawing attention to persistent challenges such as delayed diagnosis, limited treatment efficacy, and enduring clinical uncertainty. While this chapter provides essential contextual and clinical foundations, it does not examine women's lived experiences of endometriosis in the UK in depth; this is explored comprehensively in Chapter Two.

Following this clinical overview, the chapter expands to consider global experiences of endometriosis. It examines how cultural norms, stigma surrounding menstruation, reproductive expectations, and healthcare systems shape women's recognition of symptoms and access to care across different contexts.

Building on this, the chapter addresses health inequalities in the UK. It outlines structural disparities in access, quality of care, and health outcomes among minoritised ethnic groups, situating endometriosis within wider patterns of racialised and gendered inequity. This section considers how institutional bias, communication barriers, socioeconomic factors, and cultural assumptions may contribute to differential diagnostic and treatment experiences.

The chapter then engages with feminist and postcolonial feminist theory to frame the study theoretically. Feminist scholarship has long critiqued the marginalisation of women's pain and the androcentric foundations of medical knowledge (Sen, G., & Östlin, P, 2008). Postcolonial feminism further highlights how race, colonial histories, and power relations shape whose bodies are believed, whose pain is legitimised, and whose health is prioritised. These frameworks are used to interrogate how gender and ethnicity intersect in shaping healthcare encounters for South Asian women.

The philosophical and psychological dimensions of endometriosis are also explored. Chronic pain, infertility concerns, repeated medical dismissal, and uncertainty can significantly affect mental health, identity, relationships, and quality of life. The chapter considers how these psychological impacts may be compounded by cultural expectations surrounding womanhood, marriage, and fertility within some South Asian communities.

The chapter concludes by identifying key gaps in the existing literature. While research has documented women's experiences of endometriosis in the UK more broadly, there is limited work centring the voices of marginalised women specifically. This absence reflects a broader lack of intersectional research in women's health. The final section, therefore, presents the rationale, aims, and research questions of the current study, explaining how it seeks to address these gaps and contribute to both academic scholarship and healthcare practice.

## Key Terms

### *South Asian*

The term "South Asian" refers to individuals originating from the southern sub-region of Asia. Although definitions may vary across academic literature, this study adopts the classification provided by the American Psychological Association ([APA], 2019), which defines South Asians as individuals with ancestral ties to Afghanistan, Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan, and Sri Lanka. This regional grouping reflects shared, though uneven, histories of colonialism, partition, and migration that have shaped diasporic communities in the UK (Kalra, 2006).

However, the category warrants critical scrutiny. "South Asian" encompasses significant diversity in language, religion, caste, class, and migration history, and risks homogenising distinct lived experiences. Differences between Afghanistan, Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan, and Sri Lanka may be obscured within research and policy discourse. For example, the lived experiences of a Punjabi Muslim woman in India may differ significantly from those of a Punjabi Muslim woman in Pakistan, despite shared linguistic and regional heritage. Divergent national histories, minority–majority religious positioning, legal frameworks, and socio-political climates shape everyday experiences of citizenship, gender norms, and access to resources in distinct ways. These differences illustrate how the umbrella term "South Asian" can obscure internally differentiated realities structured by nation-state formation, partition, religion, and geopolitics (Mohanty, 1988). In UK contexts, the term is often further reduced to "Asian," a label that centres larger Indian and Pakistani populations while marginalising smaller or less visible groups. Globally, the meaning of "Asian" also shifts; in North America, it frequently refers to East or Southeast Asian populations, highlighting the socially constructed and racialised nature of such classifications (Kalra, 2006). Broad ethnic categories can reproduce colonial logics of knowledge production

by presenting racialised women as a homogenous group (Mohanty, 1988). In this thesis, South Asian is therefore used as a pragmatic diasporic identifier that aligns with institutional classifications and participant usage, while remaining attentive to its limitations. Where participants articulate more specific self-identifications, these are prioritised in the analysis to avoid erasure and acknowledge internal diversity.

***Women and those assigned female at birth***

The category of "women" is neither fixed nor universally agreed upon; rather, it is historically, socially, legally, and politically constructed. Feminist scholarship has long debated the meaning of "woman," challenging biological essentialism and emphasising gender as socially produced (Butler, 1990; de Beauvoir, 1949/2011). In contrast, more recent debates have foregrounded tensions between sex-based and gender identity–based definitions (Connell, 2012). These debates have intensified in the UK context, including through recent legal developments such as the 2024 UK Supreme Court ruling concerning the interpretation of "woman" under the Equality Act in Scotland, which reaffirmed a legal definition grounded in biological sex for certain statutory purposes (For Women Scotland Ltd v The Scottish Ministers, 2025). Such developments illustrate that the term "woman" carries shifting legal and political meanings that do not always align with social or experiential understandings of gender.

In this study, "women" refers to individuals who identify as women, including both cisgender women (whose gender identity aligns with their sex assigned at birth) and transgender women. At the same time, because endometriosis is a condition associated with reproductive anatomy typically linked to those assigned female at birth (AFAB), it is necessary to recognise that not all individuals who experience endometriosis identify as women. The term AFAB refers to individuals designated female at birth based on anatomical or biological

characteristics; this group includes cisgender women as well as some transgender men and non-binary people who may retain reproductive anatomy relevant to endometriosis (APA, 2020).

Where appropriate, this thesis uses the term "women and people assigned female at birth" (WAFAB) to acknowledge both gender identity and embodied experience. At the same time, when discussing existing literature, the term "women" will be retained where studies explicitly report that their participants were female or describe their samples as comprising women. This approach ensures fidelity to the original research terminology while maintaining conceptual clarity within the present study. Throughout, participants' self-identifications are prioritised to avoid imposing externally defined categories. This terminology reflects an attempt to balance inclusivity with clinical specificity, recognising that categories of sex and gender are contested and politically situated, while ensuring clarity in relation to a health condition shaped by reproductive biology. In the empirical study, all participants were assigned female at birth and identified as women, using she/her pronouns; accordingly, this thesis uses the term "women" in the title to reflect this. Throughout, participants' self-identifications are respected and prioritised in analysis.

### *Women's health*

In this study, women's health is defined as encompassing health conditions related to female reproductive anatomy alongside the wider social, economic, and structural determinants shaped by gendered inequalities (World Health Organisation [WHO], 2009). This framing reflects widely accepted public-health perspectives emphasising that women's health is shaped by both biological factors and sociocultural gender-related inequities, which influence exposure to health risks, access to care, and overall wellbeing. The WHO (2025) highlights that women's health is influenced by biological differences and gender-based social disadvantages, while broader analyses note that women's health extends well beyond

reproductive functioning, encompassing the ways gender shapes health experiences and outcomes.

***Racialised***

The term racialised refers to the social and political process through which groups are ascribed racial meanings and positioned within hierarchies of power, rather than describing inherent biological differences (Garner, 2017; Nazroo, 2020). Contemporary scholarship conceptualises race as a social construct produced through historical, political, and institutional processes that shape access to resources, opportunities, and health outcomes (Garner, 2017; Nazroo, 2020; Omi & Winant, 2015). Terms such as "ethnic minority" which in most UK research and policy contexts, is used to describe people who are not part of the White British majority population, or the now-contested "BAME (Black, Asian and minority ethnic)," homogenise diverse populations or reduce identity to demographic status (Bhavnani, 2018; Darling, 2022; Gunaratnam, 2003). The UK government formally moved away from the use of the term "BAME" following the Commission on Race and Ethnic Disparities report, which highlighted its limitations in capturing the heterogeneity of ethnic groups and recommended more precise terminology (Commission on Race and Ethnic Disparities, 2021). In line with this shift, NHS England has also moved towards more specific and inclusive ethnic categorisations in policy and reporting, reflecting a broader recognition that umbrella terms such as "BAME" can obscure important differences between ethnic groups (NHS England, 2022). The term "racialised" foregrounds the active and socially constructed processes through which certain groups are categorised and differentially positioned within systems of power. While foundational scholarship by Fanon (1967) and Collins (2000) established how race and power are structurally produced and reproduced, more recent critical race scholarship has further developed this understanding within contemporary contexts. For example, Garner (2017) and Bhavnani (2018) highlight how racialisation operates through everyday institutional practices,

while Nazroo (2020) specifically demonstrates how these processes are embedded within UK health and social care systems, shaping both access to services and health outcomes. Taken together, this literature emphasises racialisation as an ongoing structural process with tangible implications for lived experience and for inequalities in healthcare.

# Introduction

## Women's health

In recent years, there has been a notable global shift in the prioritisation of "women's health", gaining momentum across legislative, policy, and clinical practice domains. In the United Kingdom (UK), this shift has gained considerable momentum in the last ten years. The recent shift did not emerge in isolation but reflected broader social, political, and global developments. The increased visibility of women's lived experiences through social media and patient advocacy movements amplified long-standing concerns regarding gender bias, medical dismissal, and the marginalisation of women's pain within clinical settings (Samulowitz et al., 2018; Seear, 2009). This activism intersected with growing scholarly and institutional calls to integrate sex and gender more systematically into health research, as well as global policy momentum generated by initiatives such as the United Nations Sustainable Development Goals, particularly Goal 3 (Good Health and Well-being) and Goal 5 (Gender Equality) (United Nations, 2015; WHO, 2009).

Within the UK, feminist advocacy and parliamentary attention to gendered health disparities contributed to political pressure that culminated in the development of the Women's Health Strategy for England (Department of Health and Social Care [DHSC], 2022). Endometriosis-specific advocacy has also played a central role in shaping this policy agenda. Organisations such as Endometriosis UK have been key in sustaining public awareness and political engagement through campaigning, evidence submission, and the amplification of patient experiences. In addition, the All-Party Parliamentary Group (APPG) on Endometriosis has provided a formal parliamentary mechanism for translating lived experience into policy recommendations (APPG on Endometriosis, 2020). This advocacy pipeline has been reinforced by successive evidence reports highlighting systemic delays in diagnosis and care, including

the NCEPOD review, which identified significant shortcomings in the recognition and management of endometriosis within clinical pathways (NCEPOD, 2021). Furthermore, economic burden evidence has demonstrated the wider societal and productivity costs associated with delayed diagnosis and inadequate treatment (Simoens et al., 2012). These pre-existing sources illustrate that the Women's Health Strategy (Department of Health and Social Care, 2022) reflects sustained, multi-level advocacy and evidence production within the endometriosis field rather than a standalone policy development. Collectively, these forces signalled a shift toward more sustained and institutionalised engagement with women's health inequities across policy and clinical domains. This shift may also be understood within the broader move toward post-modern medicine, which increasingly positions patients as legitimate knowers of their own bodies and experiences, challenging traditional hierarchies of medical authority (Bury, 2001).

However, women's health has been a growing area of discussion since the rise of the feminist movement. The emergence of second-wave feminism in the 1970s was instrumental in raising awareness of gender disparities within healthcare (Munch, 2006). During this period, women began to challenge male-dominated medical frameworks that frequently dismissed or pathologized their health concerns, as illustrated in the seminal publication "Our Bodies, Ourselves" (Boston Women's Health Book Collective, 1971). This grassroots activism laid the groundwork for future advocacy and reform. By the 1980s, institutional recognition of gender imbalances in medical research began to gain momentum, with a growing effort to include women in clinical trials (National Institutes of Health Office of Research on Women's Health, 2023). This progression continued into the 1990s with the establishment of the Office of Research on Women's Health in the United States, further cementing the need for gender-specific health research.

At the same time, feminist activism in the UK contributed to significant social and legal changes in reproductive health. Modern contraception, including the oral contraceptive pill, was developed in the 1950s (Pincus, 1998) and became available on the NHS in 1961, initially only for married women (Macintyre & Adamson, 1988). Abortion was legalised in England, Wales, and Scotland under the Abortion Act 1967, though access remained limited and highly regulated (Richards, 2017). Feminists highlighted how reproductive control was central to women's social, economic, and political opportunities, advocating for reforms in family planning, sex education, and healthcare policy (Davis, 2018; Gleadle, 2001). Despite these advances, persistent gender disparities in healthcare remain, illustrating that the feminist movement's advocacy laid a critical foundation but that structural inequities continue to shape women's health outcomes (Holdcroft, 2007).

Within the UK, WAFAB continue to face systemic inequalities in healthcare access and outcomes. Recent global analyses indicate that the UK has one of the largest gender health gaps among high-income economies, ranking outside the top ten globally (McKinsey Health Institute, 2024). In this context, the "gender health gap" is defined as the difference in health outcomes and disease burden between women and men, measured through indicators such as disability-adjusted life years (DALYs), years lived in poor health, and disparities in access to timely diagnosis and effective treatment. These findings highlight persistent structural inequities in how health systems recognise, diagnose, and manage conditions affecting WAFAB populations. The National Health Service (NHS) Long Term Plan highlighted the urgent need to enhance the quality and safety of maternity care (NHS, 2019). Additionally, in 2021, the DHSC launched a call for evidence to inform the development of a women's health strategy (DHSC, 2021). Respondents identified gynaecological conditions as the top area of concern, underscoring the need for expanded research and improved clinical attention to women's health issues, such as endometriosis and menopause (DHSC, 2021). Among these

conditions, endometriosis stands out as a clear example in which delays in recognition, diagnosis, and treatment continue to shape women's healthcare experiences, and it is this condition that forms the central focus of the present thesis.

## Endometriosis

### *What is endometriosis?*

Endometriosis is an inflammatory condition characterised by the growth of tissue resembling the uterine lining outside the uterus (Johnson et al., 2017). This aberrant tissue growth results in inflammation and the formation of scar tissue, primarily within the pelvic region, but it can also affect other areas of the body (Burney & Giudice, 2012). It is estimated that 5-10% of WAFAB of reproductive age worldwide are affected by endometriosis (WHO, 2023). Symptoms include, but are not limited to, dysmenorrhea, dyspareunia, chronic pelvic pain, abnormal bleeding, fatigue, and, in some cases, urological or gastrointestinal symptoms, such as dysuria and dyschezia (Smolarz et al., 2021; Saunders & Horne, 2021; Pettersson & Bertero, 2020). Additionally, endometriosis is a significant contributor to fertility issues, with studies indicating that 50% of WAFAB seeking treatment for infertility present with endometriosis lesions (Saunders & Horne, 2021).

### *Diagnosis*

The diagnosis of endometriosis predominantly depends on laparoscopy, a surgical intervention that is associated with potential risks and complications (Ballard et al., 2006; Chapron et al., 1998). This is regarded as the gold standard for confirmation, typically supplemented by histological analysis (Saunders & Horne, 2021). Despite advances in clinical awareness, the average time to diagnosis remains between 4 to 10 years globally (Pugsley & Ballard, 2007; Taylor et al., 2021). Multiple factors contribute to this significant diagnostic

delay, including frequent misdiagnoses and the underestimation or dismissal of symptom severity (e.g. Taylor et al., 2021). This delay persists even though clinical guidelines in the UK recommend that patients be referred to specialist care for further investigation when symptoms are ongoing, even if initial diagnostic tests such as abdominal or pelvic examinations, ultrasounds, or MRIs yield normative results (National Institute for Health and Care Excellence [NICE], 2017). The reliance on invasive diagnostic methods, particularly laparoscopy and histology, is frequently cited as a key barrier contributing to delayed diagnosis. However, evidence suggests that a common reason for a "negative" laparoscopy in patients who do have endometriosis is a lack of specialist expertise in identifying the disease (NICE, 2017). As a result, referral to specialist centres accredited by the British Society for Gynaecological Endoscopy (BSGE) is often recommended. However, with just over 70 BSGE centres across the UK, access to specialist diagnostic services may be limited, potentially exacerbating existing geographical and socioeconomic inequalities in care.

Although non-invasive tools such as MRI and ultrasound are more than 90% specific in diagnosing endometriosis, regional disparities in access to imaging technologies and trained specialists persist (Royal College of Obstetricians and Gynaecologists [RCOG], 2023). RCOG has also emphasised that limited investment in research has hindered advancements in diagnosis and treatment (RGOG, 2023). The lack of large-scale clinical trial data continues to hinder the development of innovative diagnostic approaches and treatments, while insufficient epidemiological data prevents a comprehensive understanding of how menstrual health conditions contribute to broader health inequalities (RCOG, 2023). These delays are not without consequence; they may negatively affect reproductive potential and lead to broader functional impairments, significantly impacting quality of life (Saunders & Horne, 2021; Taylor et al., 2021). The ability to obtain a diagnosis is important as it can have positive implications such as providing WAFAB with an explanation for their symptoms, fostering a

sense of validation, and facilitating access to appropriate treatments and potential sources of support (Ballard et al., 2006; Culley et al., 2013; Young et al., 2015). Thiel et al. (2024) explored the relationship between endometriosis and subsequent mental health outcomes, finding that receiving an endometriosis diagnosis is associated with an elevated risk of developing a mental health condition, particularly within the first year following diagnosis. Despite this, there remains a notable lack of research focusing specifically on the psychological experience of receiving an endometriosis diagnosis itself. Although Thiel et al., (2024) conducted their study in the United States, their findings emphasise the importance of considering how the diagnostic process may influence an individual's overall well-being. The psychological impacts of endometriosis are explored in full later in this chapter.

***Treatment***

Treatment for endometriosis falls into four categories: medical management, surgical intervention, multidisciplinary/supportive care approaches and complementary therapies. Hormonal treatments such as combined oral contraceptives, progestins, and gonadotropin-releasing hormone (GnRH) analogues are widely used to suppress ovulation and alleviate symptoms (Brown et al., 2014; Vercellini et al., 2014). Laparoscopic treatment of endometriosis works by inserting a camera and fine instruments through small abdominal incisions to both visualise the disease and either cut out (excision) or destroy (ablation) endometriotic lesions and associated scar tissue, thereby reducing the amount of pathological tissue that can cause inflammation, pain, and fertility issues (The Royal Women's Hospital, 2025; Endometriosis UK, 2024). Excision involves dissecting and removing the lesion completely so it can be sent for pathology, while ablation uses thermal energy to burn or vaporise lesions. Excision is generally considered more thorough, especially for deeper or extensive disease (Roman, 2018). Laparoscopic surgery remains the gold standard for

diagnosis and treatment, particularly when fertility is affected or pain persists (Dunselman et al., 2014). Complementary approaches, including acupuncture and dietary changes, are used in some countries, though evidence remains limited (Armour et al., 2019). Studies frequently rely on self-reported measures of "effectiveness," yet the definition of effectiveness varies considerably across studies. For example, Armour et al. (2019) primarily evaluated reductions in pain, while broader impacts of interventions such as effects on fertility and psychosexual functioning were not addressed. In the UK, treatment approaches align with global standards and are guided by NICE (2017), which recommends a stepwise management plan including pain relief, hormonal therapy, and surgery. Hormonal treatments are typically first-line treatments, with laparoscopic surgery suggested if hormonal treatments are not effective, or for individuals who wish to conceive (NICE, 2017). However, access to care varies regionally, with long delays still prevalent despite clinical guidelines (Endometriosis UK, 2024). Thus, while treatments exist, disparities in diagnosis, access, and research remain significant.

For some individuals, available treatments for endometriosis provide only temporary symptom relief, and their limited effectiveness may contribute to feelings of frustration, despair, and anxiety (Young et al., 2015; Culley et al., 2013). WAFAB have also reported distress and offence when healthcare professionals suggest lifestyle changes, such as pregnancy or marriage, in place of evidence-based treatment options (Young et al., 2015). Furthermore, the physical side effects associated with certain treatments, including acne and weight gain, can negatively affect body image and self-esteem (Culley et al., 2013).

In addition to medical and surgical interventions, multidisciplinary and supportive care approaches are increasingly recognised as important components of endometriosis management. These approaches acknowledge the complex physical, psychological, and social impacts of the condition and may include physiotherapy, psychological interventions, specialist pain management services, and multidisciplinary care pathways (NICE, 2017; European

Society of Human Reproduction and Embryology [ESHRE], 2022). Such interventions are intended to complement biomedical treatments by supporting symptom management, psychological wellbeing, and quality of life through a more holistic and person-centred model of care (ESHRE, 2022). Contemporary guidance therefore advocates integrated approaches to care that address the multidimensional nature of endometriosis and its impact on daily functioning and wellbeing (NICE, 2024; ESHRE, 2022).

Self-management approaches are increasingly recognised as an important component of chronic condition and pain management. These approaches may include psychological therapies, lifestyle adaptations, peer support, information seeking, and strategies aimed at enhancing emotional wellbeing and symptom management (NICE, 2021). Individuals with endometriosis have described a range of self-management practices, including yoga, information seeking, and emotional and social adjustments, many of which were perceived as valuable in supporting daily functioning and quality of life (O'Hara et al., 2019). However, engagement in self-management is not without challenges. For some individuals, the responsibility of managing symptoms can be emotionally demanding and may increase anxiety or uncertainty, particularly when adequate professional support is lacking (O'Hara et al., 2019). Additionally, the burden of self-management is not only emotional but may also impose significant financial strain (Culley et al., 2013; Young et al., 2015).

***Pain***

Endometriosis is increasingly conceptualised in the literature as a chronic pain condition rather than solely a gynaecological disease (Horne & Missmer, 2022). Individuals with endometriosis report experiencing diverse and multifaceted types of pain, rather than a single, uniform symptom (e.g. Drabble et al., 2021). This commonly includes chronic pelvic pain, dysmenorrhea (painful menstruation), dyspareunia (pain during intercourse), and pain associated with bowel or bladder function, often described as sharp, stabbing, cramping, or

radiating in nature (Drabble et al., 2021; Hållstam et al., 2018). Importantly, qualitative studies highlight that these pains frequently occur simultaneously, fluctuate over time, and often extend beyond the pelvic region, becoming a persistent, whole-body experience (Williams & McGrigor, 2024).

Research suggests that endometriosis-related pain is multifactorial, involving inflammatory processes, peripheral nerve sensitisation, and alterations within the central nervous system (Morotti et al., 2017; Woolf, 2011). Because of these mechanisms, the severity of pain often does not correlate with the extent of the disease (Vercellini et al., 2007), reflecting patterns seen in other chronic pain disorders characterised by central sensitisation (Woolf, 2011). Studies consistently show that individuals with minimal or mild endometriosis may experience debilitating pain, whereas others with advanced disease report relatively limited symptoms, challenging lesion-based understandings of pathology (Morotti et al., 2017; Horne & Missmer, 2022). This inconsistency highlights a key limitation of traditional biomedical approaches, which tend to prioritise visible pathology over patient-reported experience.

Qualitative research further demonstrates that endometriosis-related pain is not only multifactorial but also deeply subjective and context-dependent. Drabble et al. (2021) describe "constellations of pain," illustrating how individuals experience multiple, shifting, and overlapping pain types that resist simple classification. Similarly, Hållstam et al. (2018) characterise living with endometriosis as an ongoing struggle for coherence, where chronic pain disrupts identity, daily functioning, and social participation. More recent syntheses emphasise that pain is closely intertwined with fatigue, emotional distress, and interactions with healthcare providers, suggesting that clinical encounters themselves can shape how pain is experienced and validated (Williams & McGrigor, 2024).

Within the literature, there are well-established medical models and theories of pain (see Melzack & Wall, 1965; Woolf, 2011 for reviews). However, theory and evidence suggest that experiences of pain are also significantly influenced by psychological factors (Penlington et al., 2019). Therefore, this discussion considers pain in relation to the Common-Sense Model of Self-Regulation (CSM).

The CSM proposes that individuals actively interpret and manage illness through personal beliefs about their condition, which guide coping behaviours and emotional responses (Leventhal et al., 2016). Individuals form illness representations across key dimensions, including identity, cause, timeline, consequences, and controllability, which influence help-seeking, coping, and treatment adherence. The model is dynamic, involving ongoing feedback loops in which individuals evaluate the effectiveness of coping strategies and adjust their beliefs accordingly. Emotional responses, such as fear and distress, operate alongside cognitive representations, shaping illness management. Importantly, the CSM does not minimise the physiological basis of pain but instead recognises that biological processes and psychological interpretations interact to shape health outcomes.

In the context of pain in endometriosis, the CSM provides a useful framework for understanding variability in pain experiences and coping. Individuals may interpret chronic pelvic pain differently depending on their beliefs about its cause, timeline, and controllability. For example, perceiving pain as uncontrollable or threatening may lead to maladaptive coping strategies, such as avoidance or catastrophising, which can exacerbate pain and disability. Conversely, beliefs that pain is manageable may promote adaptive coping and engagement with treatment. The model also highlights the impact of delayed diagnosis and medical dismissal in endometriosis, where unclear or invalidated illness representations can disrupt effective self-regulation and contribute to poorer psychological outcomes. Overall, the model demonstrates that pain in endometriosis is not solely a physiological phenomenon but is shaped

by the interaction between bodily processes, beliefs, emotions, and healthcare experiences, supporting the need for integrated, patient-centred approaches to care.

The CSM has been criticised for not fully capturing the complexity of managing chronic illness, particularly in long-term conditions (Leventhal et al., 2016; Hagger & Orbell, 2003). While it provides a useful framework for understanding how individuals form beliefs about illness and engage in coping behaviours, it's argued to oversimplify self-regulation processes by prioritising cognitive representations, while giving comparatively less attention to emotional processes, deeper cognitive mechanisms, and broader contextual influences such as social support and healthcare interactions (Moss-Morris et al., 2002). Although the model conceptualises self-management as dynamic, it may not fully reflect the non-linear and often unpredictable nature of adaptation to chronic health conditions. Furthermore, while the CSM effectively explains variability in illness perceptions and coping responses, it provides limited insight into the mechanisms linking cognition to physiological pain processes, reflecting a wider limitation across psychological theories of pain (Penlington et al., 2019). This is particularly relevant in conditions such as endometriosis, where complex interactions between biological, neurological, and psychosocial factors underpin the pain experience, suggesting that the model may benefit from integration with more explicitly biopsychosocial frameworks.

The management of pain in endometriosis is guided by recommendations such as the NICE guidelines, which advocate for a multidisciplinary and individualised approach (NICE, 2017). NICE emphasises that treatment should address both the underlying disease (through hormonal or surgical interventions) and the broader experience of pain, including psychosocial and functional impact, and that chronic pain management strategies, such as physiotherapy, cognitive-behavioural therapy, and specialist pain services, should be considered when symptoms persist (NICE, 2021). Despite this guidance, gaps remain between theoretical

frameworks and clinical practice, with many patients experiencing inconsistent treatment outcomes and delayed recognition of the chronic nature of their pain.

### *Global Experiences*

Approximately 5-10% of WAFAB have endometriosis (WHO, 2023). A systematic review examining women's experiences of endometriosis found that the condition significantly affected multiple dimensions of life, including sexual relationships, social engagement, employment, medical encounters, symptom burden, and fertility (Young et al., 2015). However, the studies in the review were largely from Anglophone countries. Using studies only from Anglophone countries introduces language and cultural bias, limiting the diversity of healthcare systems, surgical practices, and patient experiences represented in the evidence base. This restriction risks excluding high-quality research from non-English-speaking regions, reducing the global generalisability of findings and potentially skewing outcomes due to overrepresentation of high-income, English-speaking populations. As a result, the conclusions of the systematic review may not fully capture the international variability in diagnosis, management, and lived experience of endometriosis.

Despite its limitations, the review identified research gaps, particularly in relation to women's experiences of infertility associated with endometriosis and the impact of reduced social participation on perceived social support and emotional well-being. Furthermore, it highlighted a striking absence of systematic reviews or meta-analyses addressing the provision of psychological support for women with endometriosis or critically examining their interactions within healthcare systems.

To address this gap, Pettersson and Berterö (2020) systematically analysed qualitative studies to better understand how women experience encounters with healthcare professionals in the context of endometriosis. Their findings revealed that healthcare professionals often possessed inadequate knowledge of the condition and frequently failed to validate or take women's concerns seriously. The review further emphasised that the attitudes of healthcare professionals, including their willingness to listen, learn, and provide support, significantly shaped WAFAB's experiences and played a critical role in the often lengthy and distressing journey to diagnosis. Although this review provides a valuable contribution to the existing literature, several methodological limitations should be noted. First, the authors did not define what constituted a "health care" encounter, leaving the term ambiguous even though understandings of health and care vary considerably across countries, cultures, and individuals' personal interpretations (Jenkins et al., 2010). The review also reported excluding a number of studies deemed "fatally flawed," yet offered no explanation or criteria for this judgment, limiting transparency and reproducibility (Dixon-Woods et al., 2005). Furthermore, all included studies were published between 2004 and 2018, with no justification offered for selecting 2004 as the lower boundary. This is problematic given that endometriosis has been recognised and described long before this period, and important developments in diagnostic and treatment approaches predate these years (Benagiano & Brosens, 1991). Additionally, while the authors note that the included studies were conducted across multiple cultural contexts, the synthesis still relied predominantly on research from Anglophone countries. This again highlights limitations related to language, cultural representation, and generalisability. At the same time, this imbalance highlights a broader issue within the field: the scarcity of research involving participants from diverse sociocultural backgrounds. The lack of representation underscores an urgent need for more inclusive and internationally diverse studies that better reflect the varied experiences of individuals living with endometriosis.

Building upon the findings of Young et al. (2015) and Pettersson and Berterö (2020), a systematic review conducted in 2023 (see Appendix A) sought to update and expand existing literature in light of the growing recognition of endometriosis as a chronic and often debilitating illness, as well as increasing calls for reform in health policy and clinical practice. Consistent with earlier research, the review reaffirmed that WAFAB experience substantial disruption across multiple domains of their lives due to the physical, emotional, and social burden of the disease. The review identified four overarching themes. The first, barriers to care, encompassed issues such as not being heard or believed by healthcare professionals and concerns around clinicians' insufficient knowledge and clinical skills in managing endometriosis. The second theme focused on shortcomings within healthcare systems, including a lack of access to multidisciplinary care, poor-quality medical encounters, limited availability of accurate information, restricted treatment options, and persistent diagnostic delays. The third theme addressed the psychosocial burden of living with endometriosis, drawing attention to the stigma surrounding the condition and its detrimental impact on quality of life. The final theme in the review highlighted the reliance of individuals on self-care strategies, including self-advocacy and the development of individual coping mechanisms, often in response to the scarcity of formal support and systemic resources. However, in this review, a single researcher conducted the synthesis, which may have led to biased results and interpretations skewed toward the researcher's perspectives.

Nonetheless, these findings align with those of previous research, which demonstrated recurring global patterns in women’s healthcare experiences of systemic and interpersonal barriers, inadequate institutional support, and the significant personal effort required to navigate the healthcare system (e.g. Young et al., 2015; Pettersson & Bertero, 2020; Samulowitz et al., 2018). Together, this growing body of evidence illustrates the persistent challenges faced and underscores the pressing need for structural change within healthcare

systems to ensure timely, empathetic, and comprehensive care. Despite these reviews providing an important insight into the global experiences of endometriosis, the studies used across all three reviews were predominantly from Western countries. Additionally, the studies did not consider the impact of using different types of healthcare systems, or how individual differences may have played a part in experiences. The research also included studies using online questionnaires, which can be criticised for not allowing the same depth and quality of response as focus groups and in-person interviews (O'Cathain & Thomas, 2004). This highlights, once again, the importance of sustaining research efforts that reflect the full spectrum of diversity among those affected by endometriosis.

### *Psychological Experiences*

As highlighted by Young et al., (2015) literature looking at the emotional well-being of WAFAB with endometriosis is limited. This is despite the available research highlighting the overall effect endometriosis has on quality of life, including emotional well-being. Roomaney et al., (2020) reported that 43.1% of women surveyed experienced moderate to severe depression, with negative perceptions of healthcare professionals significantly predicting depressive symptoms.

A systematic review examining endometriosis and its mental health sequelae reported elevated rates of depression and anxiety among individuals with endometriosis, with prevalence estimates varying across studies but consistently indicating heightened psychological vulnerability and significantly reduced quality of life across multiple domains (Szypłowska et al., 2023). The review also identified a strong association between pain severity and increased symptoms of anxiety and depression. By selecting studies that employed quantitative outcome measures, the review enabled direct comparison of mental health outcomes across samples; however, this methodological focus limited deeper exploration of

the underlying mechanisms driving these elevated rates. More broadly, the literature on endometriosis and mental health is dominated by quantitative research, with comparatively fewer qualitative studies investigating lived experience and contextual factors.

Population-based studies further support these findings; for example, Goodwin et al. (2025) identified that both symptomatic endometriosis and chronic pelvic pain are strongly associated with increased risk of depression and anxiety, suggesting that pain severity may be a key driver of psychological distress. Similarly, Thiel et al. (2024) reported that individuals diagnosed with endometriosis face a heightened risk of developing mental health conditions, particularly within the first year after diagnosis, underscoring the psychological impact of both the disease and the diagnostic process itself.

Broader evidence syntheses confirm that anxiety and depression are among the most commonly reported mental health sequelae in endometriosis (Delanerolle et al., 2021). However, the review also noted that many of the included studies were limited by small sample sizes and cross-sectional designs, restricting the ability to infer directionality or establish causal relationships. In addition, the aims of the individual studies were not consistently reported, making it unclear whether they were intentionally designed to explore mental health outcomes or whether psychological themes emerged incidentally during analysis. Inferring mental health–related outcomes from studies that were not designed to assess them presents several methodological limitations. Such studies may not use validated psychological measures, may lack sufficient statistical power, and often fail to control for important confounding variables, thereby reducing the reliability and validity of any mental health conclusions. Additionally, post hoc interpretation of secondary findings increases the risk of overgeneralisation and may conflate improvements in physical symptoms, such as pain, with broader psychological wellbeing. Despite this, the study highlighted high rates of anxiety and depression amongst

individuals with endometriosis alongside chronic pelvic pain and dyspareunia, indicating a complex interplay between physical symptoms and emotional well-being. Together, these studies demonstrate that endometriosis is not solely a physical health condition but one with substantial psychological implications that merit further investigation.

Although the psychosocial impact of endometriosis is acknowledged, there remains a notable lack of research on psychological interventions for this population. Evans et al. (2019) conducted a systematic review examining the effectiveness of psychological and mind-body interventions for individuals with endometriosis. Their findings suggest that approaches such as cognitive-behavioural therapy, mindfulness, and yoga may help reduce pain, alleviate psychological distress, and improve quality of life for women experiencing endometriosis. The review highlights the potential benefits of integrating these holistic treatments alongside conventional medical care to address both the physical and emotional challenges associated with the condition. However, there is limited research on how WAFAB experience these interventions. Whilst some grey literature exists that has begun exploring this topic (E.g. Varney, 2020; Harpur, 2023), there is a lack of research published in peer-reviewed journals looking directly at the emotional well-being of individuals with endometriosis and the interventions to address this.

Additionally, while the psychological literature on endometriosis has predominantly focused on adverse outcomes such as anxiety, depression, distress, and reduced quality of life, there is increasing recognition that these experiences do not fully capture the complexity of living with a chronic condition. Research across chronic illness populations has highlighted processes of resilience, adaptation, and post-traumatic growth, whereby individuals may develop new coping strategies, strengthen interpersonal relationships, and derive meaning from their experiences despite ongoing challenges (Tedeschi & Calhoun, 2004; Shakespeare-Finch

& Lurie-Beck, 2014). Although this area remains underexplored within endometriosis research, emerging evidence suggests that some individuals report personal growth, increased self-advocacy, and greater self-understanding alongside experiences of distress. Recognising both adversity and resilience may therefore provide a more nuanced understanding of the psychological impact of endometriosis.

## Health Inequality in the UK

### *Health Outcomes for WAFAB and Racialised Patients*

A growing body of reports and inquiries has highlighted the harm experienced by WAFAB as a result of inadequate healthcare provision (Chen et al., 2008; DHSC, 2020a, 2020b). One particularly significant example is the inquiry into maternal health, which identified cases of preventable mortality stemming from the failure to adequately listen to WAFAB or provide appropriate medical care (Knight et al., 2014). The Women and Equalities Committee's (2024) report on WAFAB reproductive health described what it termed "medical misogyny" within healthcare systems, highlighting the routine dismissal, normalisation, and trivialisation of WAFAB pain. Drawing on patient testimonies and clinical evidence, the report found that conditions such as endometriosis, adenomyosis, and polycystic ovary syndrome are frequently subject to significant diagnostic delays, poor communication, and inadequate treatment pathways (Women and Equalities Committee, 2024). The Committee concluded that entrenched gender bias, insufficient professional training, and fragmented service provision contribute to systemic inequalities in care. The report called for improved data collection, mandatory education for healthcare professionals on women's health conditions, and stronger accountability mechanisms to address disparities in diagnosis, treatment, and patient experience.

The WAFAB findings provide an important foundational context for understanding broader patterns of healthcare access and inequality, which can then be further developed through an intersectional lens in relation to the specific experiences of racialised patients in health care.

Whilst disparities in health care systems exist amongst genders, it has also been reported that disparities exist due to other characteristics, such as race and ethnicity. The NHS Race and Health Observatory documented that individuals from racialised backgrounds encounter significant disparities in both health outcomes and access to, as well as experiences within, healthcare services when compared to white populations (Robertson et al., 2021). Specifically, an inquiry into maternity care revealed a more than four-fold difference in maternal mortality rates for women of Black ethnic backgrounds and nearly a two-fold difference for women of Asian ethnic backgrounds, relative to white women (Knight et al., 2014). However, Roberton et al., (2021) noted that the underlying causes of these disparities remain poorly understood, primarily due to a lack of high-quality research and comprehensive analysis. Although the report identified a perceived "lack of understanding," such conclusions risk privileging institutional and clinical perspectives over the voices of those directly affected. Critical scholarship has long highlighted how health research disproportionately centres dominant populations, with individuals from racialised backgrounds frequently underrepresented in study samples or excluded through methodological and epistemological standards that privilege certain forms of evidence over others (Nazroo et al., 2020). Moreover, knowledge produced within racialised communities may be devalued or dismissed as lacking rigour, reinforcing existing hierarchies of credibility within healthcare research and practice (Mirza, 2013). The MBRRACE report (Knight et al., 2014) further documented that women from racialised backgrounds reported feeling unheard and not listened to by healthcare professionals, illustrating how structural inequities are reproduced within clinical encounters.

Together, these findings underscore the importance of foregrounding patient voice and critically interrogating whose knowledge is legitimised within both research and healthcare systems.

The report by the Women and Equality Committee (Women and Equalities Committee, 2024) provides further insight into this, as it highlights concerns raised by contributors to the inquiry regarding the exclusion of women with limited English proficiency or those without internet access from healthcare services, highlighting a significant aspect of health inequalities within the UK. Specifically, WAFAB from Black African and South Asian communities reported experiencing communication barriers during healthcare consultations, which exacerbates their marginalisation within the NHS. These individuals expressed a need for more inclusive health messaging, non-digital information options, and the availability of symptom checklists to bring to medical appointments. Furthermore, healthcare professionals acknowledged the need for additional educational resources in languages such as Urdu and Punjabi to bridge the gap in healthcare accessibility for ethnic minorities. The report also notes that clinicians may, at times, rely on stereotypes regarding how racialised groups perceive medical conditions, rather than engaging with patients as individuals. These challenges contribute to the wider issue of health inequalities in the UK, where racialised groups often face compounded barriers in accessing appropriate care, thereby deepening disparities in health outcomes within the NHS.

In relation to endometriosis, emerging evidence suggests that individuals from ethnically diverse backgrounds may experience longer diagnostic delays compared with White patients (Endometriosis UK, 2026). A recent survey found that people from ethnically diverse communities waited, on average, 11 years for an endometriosis diagnosis, compared with a UK average of 9 years and 4 months, indicating persistent inequalities in diagnostic pathways (Endometriosis UK, 2026). However, there remains limited peer-reviewed literature

specifically examining ethnic differences in endometriosis diagnosis, which may reflect both a gap in empirical research and broader structural underinvestment in this area.

### *Theories and Frameworks*

Theories and frameworks of race and gender may help us to think critically about why these disparities exist. Racism manifests in various forms, ranging from overt physical violence and verbal abuse to more subtle, everyday racial micro-aggressions and insults. It can also be covert and indirect. Institutional racism refers to how societal structures, policies, and practices systematically produce unequal outcomes for racialised groups, even in the absence of overtly racist intent by individuals (Williams & Mohammed, 2013). It is embedded within the organisational culture, structures, and practices of institutions, shaping how rules are applied, who has access to opportunities, and whose knowledge or experiences are legitimised (Patel, 2022). The systemic nature of institutional racism inflicts harm across multiple levels, affecting individuals, families, communities, and institutions. Its consequences include the persistent marginalisation of racialised people, limited access to essential resources such as healthcare, employment, and education, and the reinforcement of an exclusionary and fragmented society in which certain groups are consistently disadvantaged (Patel, 2022). For example, in healthcare, institutional racism may be reflected in diagnostic criteria, treatment pathways, or leadership structures that fail to account for cultural diversity, resulting in inequitable care and poorer health outcomes for racialised patients.

Empirical research demonstrates that institutional racism significantly shapes healthcare experiences and outcomes for racialised groups. For example, qualitative and mixed-method studies within the UK maternity context reveal that racialised women encounter judgmental, stigmatising, and discriminatory care, with their personal and cultural needs often unmet in standard service provision (Thomson et al., 2022). Evidence further indicates that racialised patients report poorer experiences in primary care and insufficient support for

managing health conditions, suggesting systemic inequities in service delivery (Watkins et al., 2021; Wise, 2022). Collectively, this body of work substantiates the argument that institutional racism contributes to differential treatment, communication failures, and adverse health outcomes for racialised populations, beyond individual clinician bias.

Considering institutional racism is crucial in research on South Asian women and endometriosis because it highlights how structural and cultural barriers may shape symptom recognition, diagnostic pathways, and patient–provider interactions. Without attending to these systemic influences, research risks perpetuating narrow, biomedical explanations for disparities while overlooking how racialised assumptions and organisational practices uniquely affect the experiences, help-seeking behaviours, and outcomes of South Asian women living with long-term health conditions.

Whiteness (Fanon, 1967) provides an additional theoretical framework for understanding race and the disparities that arise from racial hierarchies. However, unlike institutional racism, the concept of whiteness centres on the system of unearned advantage, normative power, and social positioning that privileges those constructed as White. Whiteness refers to the racial power that has historically dominated society, stemming from centuries of slavery and colonialism (Patel, 2021; see also Du Bois, 1920; Fanon, 1967). It describes a system of invisible racial advantage that privileges white people, while positioning those with darker skin as inferior. Whiteness is not about being "white" as an individual trait or identity; rather, it represents a set of beliefs and practices that sustain racial hierarchies (Frankenberg,1993). This ideology shapes societal structures, institutions, and practices, keeping white individuals in positions of power and reinforcing the idea that they are superior. For example, in healthcare, the dominance of white, male, middle-class managers, often referred to as the "snowy white peaks" (Kline, 2014), reflects this imbalance. Although Kline (2014) highlighted the persistent lack of diversity among those occupying positions of power

within the NHS over a decade ago, recent workforce data suggest that these structural imbalances remain largely unchanged (NHS England, 2023). According to NHS statistics from 2022, 68.7% of professionally qualified clinical staff and 85% of individuals in management or senior management roles identified as being from White backgrounds, indicating the continued underrepresentation of racialised groups in leadership and decision-making positions. Whilst the snowy white peaks metaphor highlights the visible outcome (the dominance of certain groups), it does so without addressing the underlying systems that maintain these disparities. The underrepresentation of racialised groups in leadership and decision-making positions has significant implications for service users from these communities. Without diverse representation, policies, resource allocation, and service design may fail to reflect the specific needs, experiences, and cultural contexts of racialised populations, contributing to inequitable access and quality of care. In practical terms, this can manifest as delayed diagnoses, unmet psychosocial needs, and reduced trust in healthcare providers, reinforcing health disparities across communities (Nazroo et al., 2020; Mirza, 2013).

Theories for sex and gender-based inequalities come from feminist scholars, who argue that persistent healthcare disparities affecting WAFAB cannot be understood solely as gaps in knowledge, but as products of historically gendered systems of power. They contend that modern biomedicine developed within social and institutional structures dominated by men, shaping research priorities, diagnostic frameworks, and clinical norms around male bodies as the implicit standard (Sen & Östlin, 2008; Ussher, 2006). As a result, conditions primarily affecting WAFAB, particularly those related to pain, reproduction, and hormonal health, have often been under-researched, psychologised, or deprioritised within funding and policy agendas.

This androcentric legacy has material consequences. Feminist analyses highlight how women's symptoms are more likely to be interpreted as emotional, exaggerated, or

psychosomatic, especially in cases involving chronic pain or poorly understood conditions (Ussher, 2006). Seear (2016), for example, demonstrates how endometriosis is frequently trivialised or normalised within clinical encounters, reflecting broader cultural narratives that position menstrual and reproductive pain as expected aspects of femininity rather than indicators of pathology. Such interpretations can delay diagnosis, limit treatment options, and undermine patients' credibility as knowers of their own bodies.

Moreover, Sen and Östlin (2008) argue that gender bias in health systems operates at multiple levels: in research design (e.g., historical exclusion of women from clinical trials), in clinical practice (e.g., diagnostic overshadowing or dismissal), and in health policy (e.g., insufficient prioritisation of non-maternal reproductive health). From this perspective, disparities are not incidental but structurally embedded within biomedical knowledge production. Feminist scholarship, therefore, calls for a reorientation of healthcare that recognises gender as a social determinant of health, centres lived experience, and challenges the epistemic hierarchies that have historically marginalised WAFAB bodies within medicine.

However, feminist theory has widely been criticised as it is steeped in "whiteness" and takes on a westernised viewpoint, as it assumes that the experiences and struggles of white middle-class women in the West are representative of all women's experiences (Hooks, 2015). Crenshaw (1991) expanded upon feminist theory by proposing the concept of intersectionality, which posits that social categories such as gender, race, sexual orientation, and class are not discrete but interdependent, creating unique and compounded forms of oppression. Unlike frameworks that consider gender or race in isolation, intersectionality highlights how overlapping identities can produce distinct experiences of marginalisation. The intersection of being a woman or an individual AFAB from a marginalised background can produce unique forms of inequality, which may be intensified by additional factors influencing the quality of care received. For example, while research may document that WAFAB experience barriers in

healthcare, an intersectional lens reveals that South Asian WAFAB may face additional obstacles related to cultural expectations, language barriers, and racialised bias, resulting in delayed diagnosis or dismissal of symptoms, experiences that might be overlooked in a unidimensional, gender-only analysis. An example of this can be seen in the informal and derogatory trope often referred to as “Bibi” or “Begum syndrome,” a racialised stereotype reported within some UK healthcare contexts in which South Asian women’s symptoms are characterised as exaggerated or psychosomatic rather than clinically legitimate (Sheikh, 2022). Although not a recognised medical diagnosis, the term reflects how intersecting identities of gender, race, migration status, and language can shape credibility assessments in clinical encounters. From an intersectional perspective (Crenshaw, 1991), such stereotypes illustrate how South Asian women may experience dismissal not solely because they are women, nor solely because they are racialised, but because these identities operate together within institutional power structures. This demonstrates the analytic value of intersectionality in revealing forms of bias that would remain obscured within single-axis analyses of gender or ethnicity alone. Attention to multiple, intersecting identities can uncover nuanced patterns of healthcare inequality, informing more culturally responsive research and interventions.

In addressing institutional racism and structural inequalities, scholars have emphasised the need to create spaces that meaningfully engage with alternative narratives and lived experiences, particularly those historically marginalised within dominant social and academic discourses (e.g., Patel, 2022). Emerging in response to critiques of mainstream Western feminism, postcolonial feminism (PCF) challenges the tendency of earlier feminist scholarship to universalise the experiences of Western WAFAB while overlooking or misrepresenting women in the Global South (Mohanty, 1988). Drawing on intersectional thought, PCF asserts that gender cannot be understood in isolation from race, class, ethnicity, or colonial histories, and that these interconnected forces shape WAFAB’s lives in contextually specific ways

(Narayan et al., 2007). Central to PCF is a commitment to decolonising knowledge production by interrogating the dominance of white, Western epistemologies and by foregrounding indigenous, local, and marginalised forms of knowledge (Smith, 2021; Bhambra, 2014). In doing so, it not only challenges whose experiences are centred in research but also asks critical questions about for whom knowledge is produced and whose voices are legitimised within academic and institutional spaces.

PCF has been critiqued for sometimes overemphasising colonial histories and global power structures at the expense of local, contemporary contexts, which can obscure the specific social, political, and economic factors shaping WAFAB's experiences in particular societies (Nnaemeka, 1997). Additionally, much PCF scholarship is produced and circulated through Western academic institutions, which can inadvertently reproduce hierarchies of knowledge, privileging certain voices while marginalising others (McClintock, 1995). In the context of health research, these critiques highlight the importance of attending not only to historical and structural inequalities but also to local healthcare systems, cultural practices, and individual experiences. For South Asian women living with endometriosis, this means recognising that their healthcare encounters are shaped both by broader postcolonial and gendered inequalities and by country-specific health policies, cultural norms, and access to services. Applying PCF perspectives, therefore, requires balancing attention to global power structures with sensitivity to local and individual contexts to avoid overgeneralising the experiences of "South Asian women" as a homogeneous group.

## Philosophical and Psychological Understandings

### *Biomedical vs Postmodern*

The biomedical model is the dominant paradigm in Western medicine that conceptualises health as the absence of disease and attributes illness to biological factors that can be observed, measured, and treated through scientific methods. The model views the body

as a machine and treats disease as a mechanical malfunction that can be corrected through medical intervention (Wade & Halligan, 2004; Engel, 1977). Postmodern medicine represents a conceptual shift from the dominant biomedical model of the twentieth century, reflecting broader postmodern critiques of objectivity, authority, and universal narratives. In contrast to the positivist assumptions of modern medicine, where disease is treated primarily through scientific rationalism and technological intervention, postmodern medicine recognises the plurality of experiences, subjectivity of illness, and the importance of patient narratives (Miles, 2009; Frank, 1995).

Post-modern medicine is derived from post-modern theory, which challenges the idea that there is one single truth or objective way of understanding the world. Instead, it suggests that knowledge, identity, and reality are shaped by culture, language, and power, meaning different people can have different yet equally valid ways of understanding the same situation (Lyotard, 1984). Postmodern thinkers argue that what we perceive as "truth" is often influenced by social narratives, institutions, and historical context; therefore, it is essential to question taken-for-granted assumptions (Derrida, 1978). In this way, postmodernism emphasises multiplicity, complexity, and the notion that meaning is never fixed but continually constructed and reconstructed (Derrida, 1978; Lyotard, 1984; Foucault, 1980).

Post-modern medicine, therefore, challenges the hegemony of medical expertise by emphasising shared decision-making, contextualised care, and individual meaning-making in the experience of health and illness (Lyotard, 1984; Barry et al., 2001). It critiques the depersonalisation and reductionism of modern medical practice, instead promoting patient-centred care and valuing lived experience as a legitimate source of knowledge.

While its emphasis on patient-centred care and shared decision-making challenges biomedical dominance, critics argue that these concepts are often rhetorically endorsed but

inconsistently operationalised within structurally constrained healthcare systems (Timmermans & Berg, 2003). Additionally, some scholars suggest that post-modern critiques risk underestimating the achievements of biomedicine and may inadvertently shift responsibility onto patients by placing greater emphasis on personal meaning-making without sufficiently addressing systemic inequalities (Lupton, 1997).

Nonetheless, the post-modern perspective is particularly relevant to endometriosis, a condition characterised by complex, often invisible symptoms and significant diagnostic delay, where patients frequently report experiences of dismissal or minimisation within clinical encounters. Because endometriosis does not always present with clear biomedical markers and pain is inherently subjective, reliance on purely biomedical frameworks can marginalise patient accounts and contribute to prolonged uncertainty. Additionally, it offers a valuable conceptual framework for critically examining the cultural, social, and power structures that shape South Asian women's experiences of endometriosis. Moving beyond biomedical reductionism, it facilitates a more nuanced and inclusive understanding of how identity, stigma, and systemic inequities influence how these individuals perceive, articulate, and navigate their condition. This approach supports the development of culturally responsive research methodologies and healthcare interventions attuned to diverse patient populations lived realities. A post-modern lens foregrounds the importance of listening to and legitimising patients' narratives, recognising that experiential knowledge is essential to understanding the full psychosocial impact of the condition and to delivering responsive, person-centred care.

### *Postmodern Medicine and Illness Narratives*

Arthur Frank (1995), a central figure in the sociology of illness, characterises postmodern medicine through the concept of the "wounded storyteller," where the ill person reclaims agency by articulating their suffering in ways that resist objectification. He does not

define postmodern medicine solely by technological innovation, but by its openness to multiple truths and illness narratives that express the complexity of human experience.

Furthermore, postmodern medicine acknowledges structural inequalities, including those based on race, gender, and class, which shape access to care and outcomes. It calls for a reflexive, culturally sensitive, and ethically engaged practice that moves beyond narrow clinical efficacy (Barry et al., 2001).

Frank (1995) argues that when people become ill, their bodies disrupt their usual lives and demand attention. Illness makes the body suddenly visible; something we can no longer ignore or take for granted. Because illness is often confusing, frightening, and isolating, bodies "need voices": people need to tell stories to make sense of what is happening to them. These stories help them reclaim agency, communicate suffering, and connect with others who may understand their experience.

He goes on to discuss that illness creates a "body problem" because it undermines the sense of control and certainty people normally have about their bodies. Instead of functioning silently in the background, the body becomes unpredictable, unfamiliar, or unreliable. This disrupts who a person believes themselves to be. Illness challenges cultural ideals of independence, productivity, and autonomy, leaving people unsure of how to understand or communicate their new embodied reality.

Frank proposes that illness is fundamentally a "call for stories." When medical explanations are limited or overly technical, people turn to narrative to express the emotional, existential, and social dimensions of being ill. Stories help individuals organise the chaos of illness, seek meaning, and share their needs. They also allow others (family, clinicians, communities) to respond with compassion and understanding. Frank explains that patients often try to present themselves as "good stories" for their doctors, meaning they shape their

illness narratives to fit what they believe clinicians want to hear, hoping this will make them appear coherent, compliant, or medically legitimate. This reflects the power dynamics of healthcare, where patients feel pressure to tell stories that align with medical expectations rather than their full lived experience.

The restitution narrative is the most culturally dominant story of illness. It follows the structure: “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again.” This narrative emphasises cure, recovery, and a return to normal life. It aligns strongly with modern medicine and the biomedical model of medicine, focus on fixing and restoring the body. While comforting, Frank notes that this narrative can silence other experiences; it leaves little space for chronic illness, uncertainty, suffering, or outcomes that do not lead back to full recovery.

Chaos narratives express the feeling that life has become overwhelming, disordered, and without clear direction. These stories often lack structure or closure; they feel fragmented because the person telling them is living in a state where events seem uncontrollable. Frank stresses that chaos narratives can be uncomfortable for listeners, who may want to impose order or reassurance. However, they reveal an important and often hidden truth about illness: sometimes there is no neat meaning, only experiences of suffering.

Quest narratives depict illness as a journey that transforms the storyteller. Instead of focusing solely on curing illness, the person seeks meaning, growth, or insight through their experience. Illness becomes an opportunity to discover new values, relationships, or identities. Quest narratives often involve helping others, advocacy, community work, or supporting people with similar conditions. Frank emphasises that these stories honour suffering without reducing it simply to tragedy.

Testimony involves telling one's illness story in a way that bears witness to suffering while acknowledging that some aspects of illness may be too complex or painful to fully articulate. Testimony asks listeners to respond ethically: to hear, validate, and hold the storyteller's experience. Frank suggests that testimony is a moral act; it bridges the gap between individual suffering and collective responsibility for understanding and supporting those who are ill.

Frank uses the metaphor of the "wound as half-opening" to describe how illness reveals aspects of life that were previously hidden or ignored. A wound exposes vulnerability, dependence, and the limits of control, but it also opens possibilities for connection, empathy, and transformation. The "half-opening" suggests that while illness exposes people, it also creates new forms of understanding about the self, the body, relationships, and meaning.

Frank's (1995) framework of illness narratives challenges clinical orthodoxy by shifting authority from a purely biomedical model toward recognition of patients as meaning-makers whose lived experiences constitute legitimate knowledge. Rather than privileging restitution narratives focused on cure, his typology validates stories of chaos and quest, acknowledging that not all illness experiences resolve neatly or biomedically. In practical terms, this disrupts hierarchical consultation dynamics, encourages narrative competence and reflective listening, and reframes the clinician's role from technical expert and gatekeeper to attentive witness. Collectively, this approach broadens healthcare beyond symptom management to include the relational, existential, and moral dimensions of illness.

However, Frank's (1995) illness narrative framework has been critiqued for oversimplifying complex and evolving experiences of illness through its typologies of restitution, chaos, and quest narratives, which may not capture the fluid and culturally situated nature of storytelling (Bury, 2001). Scholars have also suggested that narrative approaches can

privilege coherence and articulate self-reflection, thereby marginalising individuals whose experiences resist structured narration or whose sociocultural contexts shape different modes of expression (Hydén, 1997). Additionally, critics argue that while Frank foregrounds patient voice, his framework pays comparatively less attention to structural determinants such as race, class, and gender that shape whose stories are heard and legitimised within healthcare systems (Williams, 2000).

Nevertheless, Frank's (1995) illness narrative framework is highly relevant to endometriosis research because the condition is often characterised by delayed diagnosis, dismissal of symptoms, and a lack of clear biomedical explanations, circumstances in which stories become a crucial way for individuals to make sense of their embodied experiences. Frank's emphasis on how illness disrupts identity, challenges bodily certainty, and calls for storytelling helps researchers capture the complexity of living with a chronic, often invisible condition. This narrative approach is also valuable when researching South Asian women's experiences of endometriosis, as it supports exploration of how cultural expectations, family dynamics, communication norms, and interactions with healthcare systems shape the telling or withholding of illness stories. Frank's concepts, such as chaos narratives, restitution narratives, and testimony, provide a structure for understanding how participants navigate uncertainty, advocate for themselves, or encounter barriers to being heard. By highlighting the ethical importance of listening to marginalised voices, Frank's work helps researchers attend to the intersection of illness, culture, and structural inequality, making it a strong fit for studies that seek to represent the lived reality of endometriosis among South Asian women. In many South Asian communities, storytelling functions as a culturally rooted practice that fosters connection, preserves shared history, and creates spaces for healing and collective meaning-making (Chris, 2025). This further highlights the strength of narrative approaches for South Asian populations, because storytelling is already a culturally embedded way of

communicating, making meaning, and processing experiences. However, considering the critiques of Frank's framework, it is important to remain attentive to alternative narrative forms and typologies, and to avoid imposing rigid interpretive structures onto participants' accounts. Care must be taken to recognise how language, cultural norms, and communicative styles shape the expression of illness experiences, so that forms of storytelling that diverge from dominant Western narrative conventions are not inadvertently marginalised. This consideration is especially pertinent when engaging with South Asian individuals, whose diverse linguistic, cultural, and social contexts may influence both the content and structure of illness narratives.

**Psychological Theories**

While Frank's narrative framework provides a valuable lens through which to interpret illness narratives, it is important to situate these accounts within broader theoretical approaches that explain how illness is experienced and negotiated. Psychological and health-related theories offer complementary perspectives, enabling analysis not only of how stories are told, but also of how emotional distress, coping, identity, and health behaviours are shaped within clinical and social contexts. Integrating these frameworks enables a more comprehensive understanding of patient experience, extending beyond narrative structure alone.

In his work, Frank (1995) highlights the role of healthcare professionals as "gatekeepers" to diagnosis, validation, and treatment, noting that patients often attempt to present themselves as a "good story" to be believed and to access care. This observation underscores the relational and institutional dimensions of illness experience, particularly the power dynamics embedded within clinical encounters. These dynamics can be further examined through patient-doctor communication theory (Street et al., 2009), which examines how interactions between clinicians and patients influence understanding, trust, decision-making, and health outcomes. This theory suggests that the way doctors and patients

communicate with each other, how symptoms are described, how concerns are addressed, and how information is exchanged can directly influence both the quality of care and the patient's emotional experience. This perspective is especially relevant to the present work, as conditions such as endometriosis often involve contested symptoms, delayed diagnosis, and experiences of dismissal (e.g. Young et al., 2015); therefore, examining communication processes helps to clarify how validation, power, and meaning are constructed within healthcare encounters (Street et al., 2009). This is also important when working with South Asian women, whose accounts may be shaped by intersecting cultural norms, gendered expectations, migration histories, and racialised dynamics within healthcare systems (Wilson et al., 2022; Culley & Hudson, 2006). Attention to communication processes enables a more nuanced understanding of how symptoms are articulated, interpreted, and legitimised, and helps to identify potential sites of misunderstanding or inequity that may contribute to disparities in recognition, diagnosis, and care (Street et al., 2009; Nazroo et al., 2020).

While post-modern medicine and discourses around illness narrative emphasise meaning-making and identity reconstruction in the context of disrupted life stories, adjustment theory (Taylor, 1983) shifts the focus toward the psychological processes through which individuals cognitively and emotionally adapt to chronic illness over time. Adjustment Theory explains how individuals cope with and adapt to chronic illness by balancing the demands of the illness with their psychological and social resources. It emphasises that successful adjustment depends on factors such as illness perception, coping strategies, social support, and cultural context (Taylor, 1983). This theory highlights the dynamic process through which individuals redefine their identity, manage emotional distress, and modify behaviour to maintain a satisfactory quality of life despite ongoing health challenges. This focus on personal experience, identity reconstruction, and the influence of social and cultural contexts aligns closely with the principles of postmodern medicine. Thus, Adjustment Theory complements

postmodern medicine by providing a framework that acknowledges the complex, individualised, and contextualised ways in which people experience and manage chronic illness. For example, a South Asian woman living with endometriosis may need to renegotiate aspects of her identity related to expectations of marriage, fertility, and caregiving roles that may hold particular cultural significance, while simultaneously managing chronic pain and uncertainty. Adjustment, in this context, involves not only psychological adaptation to symptoms but also the reworking of culturally embedded understandings of womanhood and health, illustrating how coping processes are inseparable from social and cultural identity.

***Integration and Application to South Asian Women***

South Asian women in the UK navigate layered social expectations shaped by gender, race, migration histories, and socio-economic positioning. Within many South Asian communities, women are often understood as upholding family reputation and cultural continuity, with norms surrounding modesty, marriage, and sexuality carrying collective significance beyond the individual (Afshar, 1989; Wilson, 2006). At the same time, dominant Western discourses have frequently constructed South Asian women through reductive narratives of victimhood or cultural oppression, positioning them as passive subjects in need of rescue (Mohanty, 1988; Brah, 1996). Within health and social care systems, these intersecting assumptions can manifest in women being labelled as "difficult to engage" or "non-compliant," obscuring the structural and communicative barriers that shape service access (Chew-Graham et al., 2002).

Evidence also suggests that South Asian women may experience psychological distress in ways that are closely tied to stigma, intergenerational expectations, and racialised experiences, while facing barriers such as limited culturally responsive services, language constraints, and practical obstacles to care (Bhui et al., 2003; Hussain & Cochrane, 2004). Furthermore, research has often treated ethnic minority populations as homogenous categories,

failing to account for differences across religion, migration status, and class, and thereby rendering the specific experiences of South Asian women less visible within mainstream scholarship (Nazroo, 1997). Taken together, these intersecting social and structural factors provide important context for understanding how South Asian women may experience and negotiate chronic and reproductive health conditions within both community and healthcare settings.

Integrating narrative theory, post-modern medicine, and theories of adjustment and communication provides a multidimensional framework for understanding the experiences of South Asian women with endometriosis. Together, these perspectives foreground lived experience, illuminate power dynamics within healthcare encounters, and recognise the culturally situated processes of identity reconstruction and coping. Applying this integrated approach enables a more culturally responsive analysis of how symptoms are interpreted, communicated, and legitimised, while also attending to the structural and relational factors that shape healthcare access and outcomes. Together, these approaches support the development of culturally responsive research methodologies and healthcare interventions that are attuned to the lived realities of diverse patient populations.

**Framing the current study**

Whilst research has begun to explore the experiences of women with endometriosis more broadly, there remains a notable gap in research focusing specifically on the experiences of women from racialised backgrounds. This is despite evidence suggesting a higher prevalence of endometriosis among Asian women compared to their White counterparts (Bougie et al., 2019; Farland & Horne, 2019; Sangi-Haghpeykar & Poindexter, 1995). The limited research that does exist highlights the unique sociocultural factors shaping these experiences.

Denny et al., (2011) explored understandings of endometriosis among women from a range of backgrounds in the UK using focus groups, including Indian, Pakistani, African Caribbean, Chinese, and Greek/Greek Cypriot participants. Although many women across groups demonstrated low awareness of endometriosis and perceived symptoms such as painful menstruation as "normal," the findings highlighted cultural differences in how reproductive health, menstruation, and fertility are understood, with stigma around discussing menstrual pain and social pressures related to motherhood appearing especially pronounced in South Asian groups. Women described embarrassment talking about intimate symptoms, concerns about community and family judgment, and differing help-seeking preferences, suggesting that sociocultural norms shape the interpretation and communication of symptoms. These results underscore the importance of recognising socio-cultural context in healthcare provision and suggest that universal clinical approaches may overlook culturally specific barriers to recognition and help-seeking, a key consideration when researching endometriosis experiences among South Asian women (Denny et al., 2011).

Furthermore, Hudson et al. (2016) did not focus exclusively on ethnic differences, but their study intentionally included South Asian couples alongside White British participants to capture diverse experiences of endometriosis within relationships. The study acknowledged that cultural expectations around marriage, fertility, and gender roles may shape how couples interpret and respond to the disruptions caused by endometriosis. This inclusion points to the importance of understanding how biographical disruption may interact with culturally specific norms and expectations, particularly around marriage and childbearing, which can be especially salient in South Asian contexts. Although the article does not present separate ethnicity-specific findings, its methodology highlights that cultural background can influence how illness is experienced, narrated, and negotiated within relationships, underscoring the need for intersectional analysis in future research on endometriosis and marginalised groups

The findings from this empirical research align with wider research focusing on South Asian women, which indicates that cultural and religious ideologies can create intersecting pressures that intensify the physical and psychological burden of endometriosis (Wilson et al., 2022). Within some South Asian communities, menarche, signifying physical maturity and perceived readiness for marriage and reproduction, is often surrounded by silence and stigma. At the same time, menstruation may be constructed as taboo and accompanied by restrictive practices relating to work, sexuality, diet, and hygiene (Wilson et al., 2022). These norms can perpetuate silence around menstrual health and contribute to intra-community discrimination, further marginalising women within both gendered and racialised contexts. Cultural differences in the expression of distress may further complicate recognition of symptoms; research has shown that in some South Asian communities, emotional distress is more commonly communicated through physical complaints (somatising), including pain (Raguram et al., 2001). When clinicians interpret such presentations through Western biomedical frameworks without cultural understanding, symptoms may be misattributed or minimised.

Importantly, this aligns with wider UK research on reproductive health among South Asian women. For example, Culley and Hudson (2006) found that infertility within British South Asian communities is deeply socially embedded, with strong pronatalist expectations placing considerable pressure on women to conceive and exposing them to stigma and social scrutiny when reproduction is disrupted. Together with previous endometriosis research highlighting the specific support needs of South Asian women, these findings suggest that reproductive conditions are experienced not only as biomedical events but as socially situated disruptions shaped by cultural expectations around womanhood and fertility.

Given the high prevalence of endometriosis in the UK and emerging evidence of ethnic health inequalities, there is a clear need to further investigate the lived experiences of South Asian women with endometriosis to inform culturally responsive research and care practices.

## Aims and Objectives

This research aims to address the limited empirical literature concerning South Asian women diagnosed with endometriosis in the UK by exploring how cultural, relational, and structural factors shape their experiences of illness, diagnosis, and care. Grounded in intersectional and culturally informed frameworks, the study seeks to foreground the voices of women whose experiences are frequently underrepresented in endometriosis research and to generate knowledge that may inform more equitable healthcare provision.

Specifically, the study will:

- Explore how women from diverse South Asian backgrounds experience their journeys to diagnosis, including symptom recognition, help-seeking behaviours, interactions with healthcare professionals, and perceived barriers or facilitators to timely diagnosis.
- Examine how cultural, familial, and community contexts influence the meaning-making of endometriosis, particularly in relation to menstruation, fertility, marriage, and gendered expectations.
- Investigate how intersecting identities (e.g., gender, ethnicity, migration history, religion, and language) shape experiences of validation, dismissal, or support within healthcare encounters.
- Identify the clinical implications of these findings for service provision, with particular attention to culturally responsive communication, patient–doctor relationships, and structural barriers within healthcare systems.
- Generate recommendations for improving support pathways and care practices for South Asian women living with endometriosis, contributing to the development of more inclusive and equitable reproductive healthcare services.

Through these objectives, the study aims not only to document lived experiences but also to inform practice and policy in ways that meaningfully address disparities in endometriosis care, whilst addressing the research question *"How do South Asian Women experience endometriosis in the UK?"*.

Before exploring the experiences of South Asian women, it is important to first consider the broader experiences of women diagnosed with endometriosis in the UK. Accordingly, Chapter Two presents a systematic review of the existing literature to provide an overview of current knowledge in this area.

# Chapter Two: Understanding the experiences of Women with Endometriosis within the UK, A Meta-ethnographic Synthesis


## Abstract

**Background:** Endometriosis is a chronic inflammatory disease of the uterus that can affect all areas of a woman's life: sex, social life, work, medical experiences, symptoms, and infertility. It has been suggested that women often face a difficult journey in acquiring a diagnosis and receiving treatment for symptoms, yet there is currently no review of the literature within the UK surrounding women's experiences.

**Methods:** This meta-ethnography included seventeen qualitative studies to examine women with endometriosis' experiences within the UK.

**Results:** The synthesis revealed a unique understanding of women's experiences which can be conceptualised on four different levels: diagnostic and healthcare challenges, physical and symptom experience, psychosocial impact, coping and self-advocacy. The findings illustrate the multiple difficulties women face and how they are interlinked, creating a cycle of suffering.

**Conclusion:** This synthesis revealed the need for change within healthcare systems at multiple levels, such as increased access to professionals and better training. More research exploring experiences of using the UK health system is needed to better understand how needs can be addressed, especially within specific groups of women.

## Introduction

In the UK, one in ten individuals assigned female at birth of reproductive age have endometriosis (Endometriosis UK, 2024; House of Commons Women and Equalities Committee, 2024). The demand for gynaecological services in the NHS has grown faster than any other speciality (House of Commons Women and Equalities Committee, 2024). Explanations for this include backlogs following the coronavirus pandemic (Royal College of Obstetricians & Gynaecologists, 2022), suggestions that gynaecological care was historically deprioritised compared to other surgical specialities (House of Commons Women and Equalities Committee, 2024; Royal College of Obstetricians & Gynaecologists, 2022), and increased awareness of gynaecological conditions (Endometriosis UK, 2024). In June 2024, there were 763,694 individuals on the waitlist for gynaecological care with the NHS (House of Commons Women and Equalities Committee, 2024). The average diagnostic delay for endometriosis now stands at eight years and ten months, a figure that has worsened following the coronavirus pandemic (Endometriosis UK, 2024).

A 2024 report by Endometriosis UK, based on a survey of 4,371 individuals, highlighted widespread diagnostic challenges: nearly half of respondents had seen their general practitioner (GP) ten or more times before receiving a diagnosis, while 70% had visited at least five times. Furthermore, 52% had attended Accident and Emergency (A&E) services, and 20% had seen a gynaecologist ten or more times prior to diagnosis (Endometriosis UK, 2024). This pattern of repeated healthcare visits underscores significant delays in diagnosis, leading to prolonged pain, disease progression, and avoidable physical and psychological distress for patients. It also places a substantial

burden on healthcare services, reflecting inefficiencies in recognising and managing endometriosis at earlier stages.

There is also evidence of dismissive attitudes from clinicians, with 78% of respondents in 2023 reporting that a healthcare professional had told them they were "making a fuss about nothing," an increase from 69% in 2020 (Endometriosis UK, 2024). This reflects broader systemic issues, including a lack of urgency in diagnostic procedures. Research commissioned by the UK Government to inform the Women's Health Strategy found that some primary care professionals believed that a formal diagnosis was unnecessary if symptoms could be managed in primary care (Department of Health & Social Care [DHSC], 2021).

Symptom onset often begins during adolescence, yet young patients are frequently dismissed (Randhawa, 2023; Endometriosis UK, 2024; House of Commons Women and Equalities Committee, 2024). The House of Commons Women and Equalities Committee reported that women are being told they are too young to have endometriosis, despite age not being a diagnostic criterion (House of Commons Women and Equalities Committee, 2024; NICE, 2017). Financial considerations within the NHS have also influenced care pathways; for example, the suggestion that £6.6 million could be saved by moving 75% of endometrial ablations to outpatient care has raised ethical concerns. The Campaign Against Painful Hysteroscopy warned that such cost-saving measures risk overlooking the severity of pain experienced by patients during these procedures (House of Commons Women and Equalities Committee, 2024; Campaign Against Painful Hysteroscopy, 2016).

A 2023 systematic review looking into healthcare experiences of endometriosis globally found a strong association between chronic pain associated with endometriosis and higher rates of anxiety and depression, underscoring the importance of integrating

mental health support into treatment pathways (Harris et al., 2023). The higher rates of anxiety and depression likely reflect the profound psychological burden of ongoing pain, uncertainty, and impact on daily functioning. Symptoms of chronic pelvic pain and persistent discomfort not only interfere with physical functioning but also exacerbate emotional distress, contributing to elevated rates of mood disorders in affected individuals (Szypłowska, Tarkowsk & Kułak, 2023). However, mental health provision remains inconsistent across the UK, with many services being generic and failing to meet the specific needs of women with reproductive ill health (House of Commons Women and Equalities Committee, 2024; The National Confidential Enquiry into Patient Outcome and Death, 2024).

In 2018, a search of the UK Research and Innovation (UKRI) awards database for the term "endometriosis" yielded 35 results, indicating that 35 research projects related to endometriosis had received funding since 2003. The body of UK-based research exploring the experiential dimension of endometriosis remains underdeveloped, with a limited number of studies dedicated solely to women's subjective accounts (Jones et al., 2020). Despite this, there is currently no synthesis available looking at the findings from UK studies. A systematic review is widely regarded as the gold standard for synthesising research evidence due to its methodological rigour, transparency, and replicability (Moher et al., 2009). Therefore, this systematic review aims to update the current literature by providing a review of the research within the UK.

The exploration will involve synthesising contemporary research to offer the first review of the literature within the UK. In order to review the current research surrounding endometriosis within the UK, the following research question was formulated: *How do*

*women in the UK experience endometriosis?* This study aims to enhance the understanding of women's experiences.

# Methods

## Design

While traditional meta-analyses have largely focused on quantitative data, more recent approaches have been developed to synthesise qualitative research (Atkins et al., 2008; Campbell et al., 2003; Pound et al., 2005). Among these, Noblit and Hare's (1988) meta-ethnographic approach offers an interpretative framework that uses a seven-phase process to organise and integrate findings from multiple studies, capturing a range of perspectives (Priestley & McPherson, 2016). Through systematic comparisons of key concepts, meta-ethnography identifies areas of convergence, contradiction, or distinct representation across studies (Priestley & McPherson, 2016). This method has proven particularly valuable in examining healthcare experiences, including those of chronic illness (Britten et al., 2002; Atkins et al., 2008). Its strength lies in preserving the richness of qualitative data while enabling interpretative synthesis across diverse studies (Atkins et al., 2008). For this reason, the meta-ethnographic approach was selected to explore the lived experiences of endometriosis in the UK. The present study followed Noblit and Hare's (1988) seven-phase process: identifying the research focus; selecting relevant studies; engaging in detailed reading; determining interrelationships between studies; translating studies into one another; synthesising translations; and presenting the synthesis.

## Article Selection

### *Search terms*

To define the topics of interest and guide the search strategy, the SPIDER framework was applied (Cooke et al., 2012) (Table 1). It focuses on five elements: Sample**,** Phenomenon

of Interest**,** Design**,** Evaluation**,** and Research Type**.** This framework supports the development of transparent and targeted searches by aligning key aspects of qualitative inquiry with relevant search terms. The review included articles that employed qualitative methods to explore the experiences of women with a confirmed diagnosis of endometriosis in the UK. The decision was made to include grey literature (e.g. theses), in addition to papers published in peer-reviewed journals, due to the scarcity of literature in the current field and the need to hear as many participant voices as possible. Qualitative methods were defined as face-to-face interviews, focus groups, or questionnaires with free-text responses followed by in-depth analysis.

**Table 1.**

*SPIDER criteria for study eligibility and inclusion*

| Criteria | Definition |
|---|---|
| Sample | Women with a diagnosis of endometriosis |
| Phenomenon of interest | In the United Kingdom |
| Design | Interviews, focus groups |
| Evaluation | Views, experiences |
| Research type | Qualitative |

### *Inclusion Criteria*

Studies were included if participants had a medically confirmed diagnosis of endometriosis, verified through procedures such as laparoscopy or imaging. Mixed-methods studies were eligible when qualitative data were analysed and presented independently. Studies looking at couples' experiences were included if they reported the findings from each partner separately. No publication date limit was applied to ensure the inclusion of all relevant studies available up to the date of the search.

### *Exclusion Criteria*

Studies were excluded if they combined data from participants with endometriosis and those with other conditions (e.g., polycystic ovary syndrome or adenomyosis) without reporting findings separately and/or included the views of other stakeholders (e.g. GP's). Research on couples where it was not possible to stratify between the patient with endometriosis and their partners' perspectives were also excluded. Studies were not excluded if participants with endometriosis also had comorbid gynaecological conditions, provided that the study focused on endometriosis and reported findings specifically for participants with endometriosis.

### *Search Strategy*

An electronic search was conducted using databases CINAHL Ultimate, APA PsycINFO, APA Psycharticles, MEDLINE Ultimate, and SCOPUS in October 2025. The search criteria were refined using the limiters 'English language" and 'Title and Abstract'. The search terms employed are seen in Table 2.

**Table 2.**

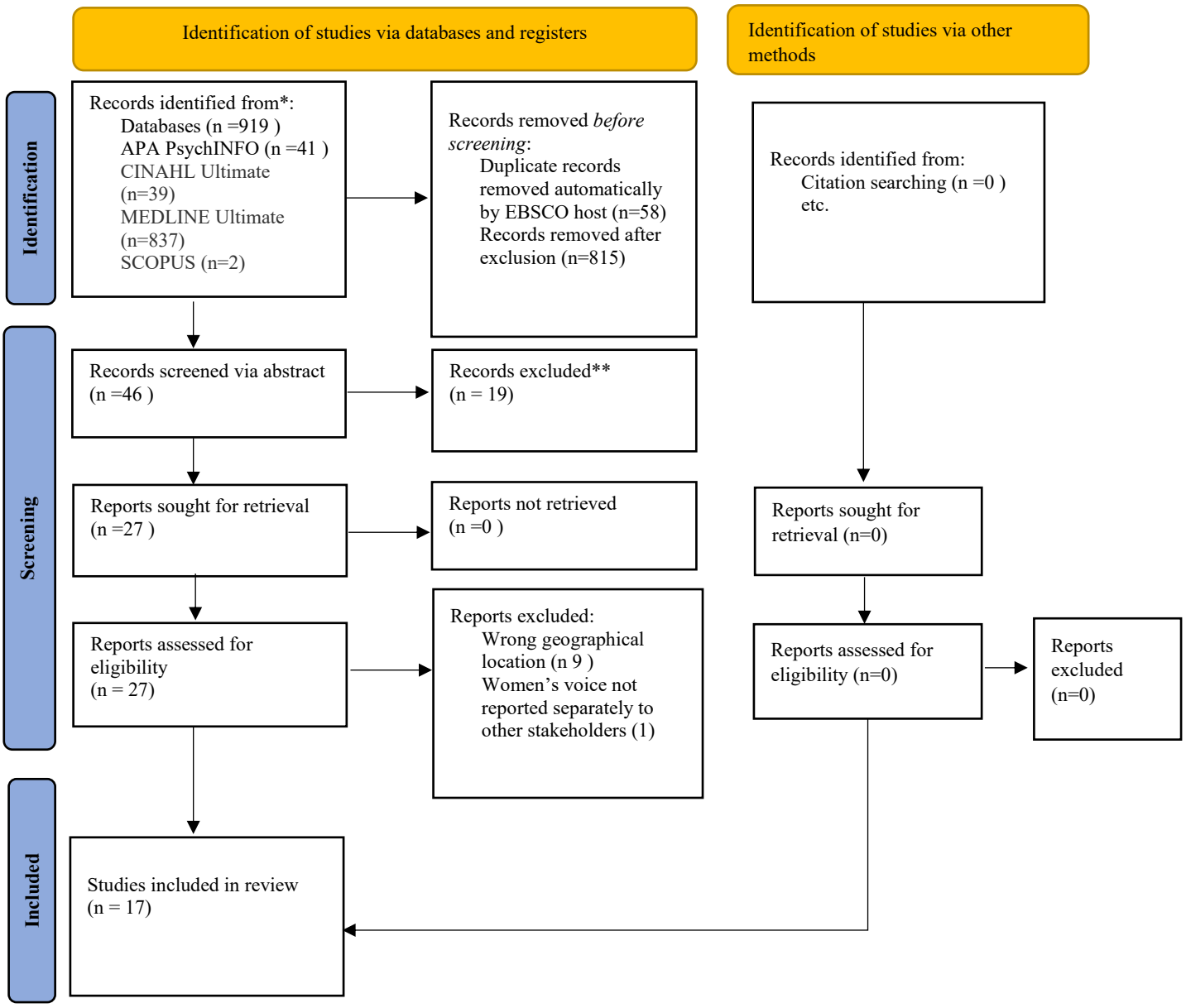
*Search terms used to retrieve articles*

| Search Number | Search Term |
|---|---|
| 1 | wom?n, woman* or female or girl or patient |
| 2 | endometrio* |
| 3 | "United Kingdom" OR UK OR Britain OR "Great Britain" OR England OR Scotland OR Wales OR "Northern Ireland" |
| 4 | experience* OR perception* OR perspective* OR attitude* OR opinion* OR view* OR interpretation* OR "lived experience*" OR "personal experience*" OR narrative* OR "life stor*" OR journey* OR account* OR coping OR adaptation |
| 5 | qualitative OR phenomenol* OR ethnograph* OR "grounded theor*" OR hermeneutic* OR heuristic* OR "discourse analysis" OR "thematic analysis" OR "content analysis" OR "framework analysis" OR "thematic synthes*" OR "narrative analysis" OR interview* OR "focus group*" OR "field stud*" OR "case stud*" |
| 6 | S1 AND S2 AND S3 AND S4 AND S5 |
| 7 | Limiters: English language |

The journal titles and abstracts were then scanned in detail; seventeen were selected for inclusion. The reference lists of the selected journals were then searched to identify further relevant literature; no additional studies were found.

**Figure 1.**

*PRISMA flow diagram showing the search process (Page et al., 2021).*



# Analysis

## Reading the studies

An in-depth review of the seventeen selected papers was conducted to identify recurring patterns and shared experiences. The lead researcher repeatedly read each study to ensure full immersion in the data and a clear understanding of key concepts. A table was created for each study outlining key concepts (themes), first-order constructs (participant quotes), and second-order constructs (primary author interpretations). An example can be seen in Table 3.

**Table 3.**

*Sample of key concepts and constructs for Wren and Mercer (2022).*

| Themes | Second Order Constructs | First order constructs |
|---|---|---|
| The pursuit of a diagnosis | Women faced prolonged diagnostic journey, beginning in early puberty and culminating in diagnosis. Delays were linked to ineffective clinical practices and age-related dismissal | "I kind of saw the surgery as like the light at the end of the tunnel" |
| Adjusting to a new normality | As participants moved through their diagnostic journey, they highlighted the need to establish a new sense of normality and identity, particularly during adolescence and young adulthood. | "…my only goal in life that's been like stable throughout my entire life is wanting to have a family I was like it's literally going to be taken" |
| The importance of affective support | Participants relied on diverse support networks to manage emotional distress and enhance well-being during their diagnostic journeys. These supports often compensated for limited clinician guidance. | "My Dad or Mum would like she just like drop anything and like come and pick me up" |

**Determining how the studies are related**

Following the method outlined by Noblit and Hare (1988), a list of themes across all studies was created to systematically organise and compare themes. This list was then refined using thematic analysis, resulting in the identification of twelve key concepts that capture the breadth of women's experiences with endometriosis. These newly developed categories were labelled using terminology that captured the full range of concepts they represented. The concepts that emerged were: prolonged diagnostic journey, dismissal and minimisation of symptoms, communication barriers and health-seeking behaviour, multifaceted pain experiences, impact on daily life and identity, emotional and psychological distress, fertility and reproductive concerns, interactions with healthcare systems and access to care, stigma and societal influences, sexual health and intimacy, coping strategies and resilience, and navigating knowledge and self-advocacy.

**Translating the studies into one another**

After developing summary tables for each study, the analysis concentrated on identifying overarching themes across all included papers. As noted by Atkins et al. (2008), reviewing studies sequentially can influence the interpretation of themes that emerge later in the process. To reduce this potential bias, the researcher remained receptive to new or evolving themes throughout the analysis. The final themes were then synthesised into a comprehensive table (Table 4) to facilitate comparison of shared concepts across studies.

**Table 4.**

*Cross-comparison of studies by concept*

| **Concepts** | Ballard, Lowton & Wright (2006) | Clark (2012) | de C Williams et al., (2022) | Denny & Mann (2007) | Denny & Mann (2008) | Denny (2004) | Denny (2009) | Drabble et al., (2021) | Grogan, Turley & Cole (2018) | Grogan, Turley & Cole (2021) | Harpur (2023) | Jones, Jenkins & Kennedy (2004) | Karavadra et al., (2025) | Law et al., (2024) | Taylor (2004) | Varney (2022) | Wren & Mercer (2022) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Prolonged diagnostic journey | * | * | * | | * | * | | | | | | * | * | | * | | * |
| Dismissal and minimisation of symptoms | * | * | * | | * | * | | | * | * | * | * | * | | * | * | * |
| Communication barriers and health-seeking behaviour | | * | | | * | | | | | * | * | | | | * | | * |
| Multifaceted pain experiences | | * | * | | | * | * | * | | * | | * | | * | | | |
| Impact on daily life and identity | * | * | * | * | | * | | * | * | * | | * | | * | | | |
| Emotional and psychological distress | | * | * | * | | | * | * | * | * | * | * | * | * | | * | |

**Table 4 continued.**

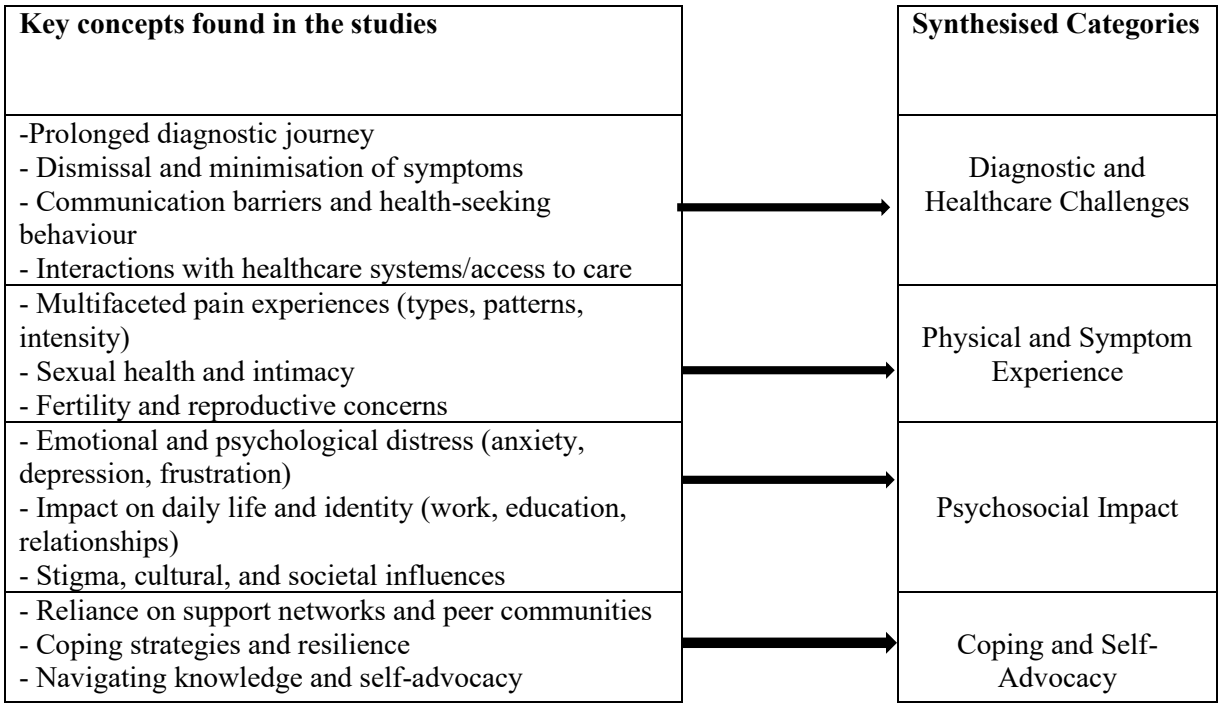
*Cross-comparison of studies by concept continued*

| **Concepts** | Ballard, Lowton & Wright (2006) | Clark (2012) | de C Williams et al., (2022) | Denny & Mann (2007) | Denny & Mann (2008) | Denny (2004) | Denny (2009) | Drabble et al., (2021) | Grogan, Turley & Cole (2018) | Grogan, Turley & Cole (2021) | Harpur (2023) | Jones, Jenkins & Kennedy (2004) | Karavadra et al., (2025) | Law et al., (2024) | Taylor (2004) | Varney (2022) | Wren & Mercer (2022) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Fertility and reproductive concerns | | * | * | | | | | * | | * | | * | * | | * | | * |
| Interactions with healthcare systems/access to care | | | | | * | | | | | | | * | * | | * | * | |
| Stigma, cultural, & societal influences | * | | | | | | | | * | * | | | | * | * | * | |
| Sexual health and intimacy | | | * | * | | * | * | | | * | | * | | * | | | |
| Coping strategies and resilience | | * | | | | | * | | * | * | | | * | | | | * |
| Navigating knowledge & Self-advocacy | | * | | | | | | | * | | * | | * | | * | | |

**Synthesising the translation**

Although replicating the synthesis process in its entirety is inherently challenging, this meta-ethnography followed the method described by Atkins et al. (2008). Data from each study were systematically organised into tables and examined side-by-side, allowing for a detailed cross-comparison of first and second-order interpretations. Through this process, concepts from the individual studies were translated reciprocally, reflecting the similarities in experiences across the research (Britten et al., 2002; Noblit & Hare, 1988). From these comparisons, twelve initial themes were identified and subsequently grouped into four overarching categories: diagnostic and healthcare challenges**,** physical and symptom experiences**,** psychosocial impact**,** and coping and self-advocacy. These categories were further refined to develop a line-of-argument synthesis, integrating second-order interpretations and highlighting the interconnections between women's experiences, healthcare interactions, and self-management strategies (Figure 2).

**Figure 2.**
*Summary of key concepts and synthesised categories.*




## Results

### Quality assessment

Authors who have conducted meta-ethnographies have differing opinions on how to apply quality assessment. Some choose to exclude low-quality studies (Fosse et al., 2014), while others refrain from excluding any studies and, instead, utilise the quality assessment data to determine each study's contribution to the synthesis (Atkins et al., 2008). The current meta-ethnography used an adapted version of the CASP (Critical Appraisal Skills Programme UK, 2018). Whilst the CASP checklist is traditionally scored dichotomously, assigning a score of 1 when a criterion is met and 0 when it is not met or cannot be determined, this study adopted a modified scoring approach. Specifically, criteria were scored as 1 when fully met, 0 when not

met, and 0.5 when partially met or where insufficient detail was provided to make a definitive judgement (CASP, 2018). This modification was implemented to allow greater sensitivity in the appraisal process, as several included studies provided limited or incomplete information for certain criteria. The inclusion of an intermediate score enabled differentiation between studies that did not meet a criterion and those that demonstrated partial fulfilment or ambiguity, thereby enhancing the nuance and interpretability of the quality assessment (Long et al., 2020).

All articles were included, regardless of quality. This approach mirrored Atkins et al.'s (2008) choice to include all journals that fulfilled their predetermined basic criteria, with the assumption that peer-reviewed journals maintain a good level of quality. Grey literature was also included regardless of CASP score due to the minimal literature in the area and the need for further research in the area.

The results of the CASP analysis suggested varying quality across the studies (Appendix B). All studies were given equal consideration within the synthesis, and higher-quality studies were not used to anchor key concepts. This approach was adopted to remain consistent with the principles of the PCF, recognising that variations in CASP scores may reflect differences in publication format rather than methodological rigour. For example, journal articles are often constrained by word limits and reporting requirements, whereas theses typically provide greater scope for detailed discussion of methodological and analytical issues that are assessed within the CASP criteria. Fifteen studies provided clear research aims, whilst two gave vague aims (de C Williams et al., 2025; Denny & Mann, 2008). Atkins et al., (2008) suggest that having a clear research aim is the most important step in carrying out research; the absence of this could contribute to the overall lower quality of research compared to other studies in the synthesis.

All studies clearly described recruitment strategies that were appropriate to their research aims, except for de C Williams et al. (2025), who noted that participants were drawn from a larger study but did not specify the selection process. Another study reported recruiting from a clinic but did not report how participants were selected from the clinic (Ballard, Lowton & Wright, 2016). Additionally, most studies recruited participants through social media platforms, support groups, and endometriosis charities (Wren & Mercer, 2022; Grogan, Turley & Cole, 2018; Law et al., 2025; Drabble et al., 2021; Harpur, 2023; Varney, 2020; Denny, 2004; Taylor, 2024; Clark, 2012; Cole, Grogan & Turley, 2021). However, research suggests that individuals who engage with such networks may do so because they experience limited personal support, and consequently, their accounts may reflect more challenging experiences, potentially influencing study findings (van der Zanden et al., 2022; Whitaker et al., 2017).

All studies used face-to-face or online interviews, apart from two, which used online surveys with open-ended questions (Grogan, Turley & Cole, 2018; 2021). Although the researchers stated this was to encourage disclosure, written accounts may not be as appropriate as interviews for qualitative research because they often lack the depth, nuance, and opportunity for probing that interviews provide, limiting the richness of participants' responses and the ability to explore complex experiences in detail (O'Cathain & Thomas, 2004). Interviews allow researchers to clarify meaning, follow up on emerging topics, and capture emotional and contextual subtleties that written responses may miss.

Whilst all studies provided a description of their data analysis methods, several offered only vague or limited explanations of how the analysis was conducted, giving little insight into the specific processes, coding frameworks, or steps taken to ensure rigour and transparency (Denny, 2004; Denny and Mann, 2007; Denny and Mann, 2008; Wren and Mercer, 2022). In these cases, authors referred broadly to "thematic analysis" or "interpretative methods" without elaborating on how themes were generated, refined, or validated. This lack of methodological

clarity reduces replicability and makes it difficult to fully assess the trustworthiness and depth of interpretation within these studies (Nowell et al., 2017).

Ethical approval was sought in all papers. Despite all studies referring to the process of ethical approval, only two studies provided further detail about the consideration of ethical issues during the recruitment and interview process (Clark, 2012, Taylor, 2024), and only two studies discussed how ethical issues were managed during the interview process (Harpur, 2023; Drabble et al., 2021). Seven studies had a particularly small sample size (n<20) (Wren & Mercer, 2022; Williams et al., 2025; Denny et al., 2025; Harpur, 2023; Varney, 2022; Taylor, 2024; Karavadra et al., 2025), which was acknowledged by some of the authors who stated findings may not be representative of the wider population.

The studies were carried out in varying areas of the UK. Nevertheless, most of the study samples were considered homogenous in age, education level, marriage status, and sexual identity. One study failed to report any demographic information about participants (Denny, 2004). Whilst one study focused specifically on a subgroup of women from black backgrounds (Taylor, 2024), most studies participants were White British (Appendix C). Law et al., (2025) purposively included a sub-sample of South Asian couples due to research indicating there are ethnic differences in experiences, and another study acknowledged the underrepresentation of women from “minority ethnic backgrounds in pain research (Williams et al., 2025). Several of the studies acknowledge the limitations in their sample (Denny & Mann, 2007; Drabble et al., 2021; Grogan et al., 2018; Kavandra et al., 2025; Varney et al., 2020; Wren et al., 2022). This suggests that the results of these studies are not generalisable to women generally in the UK as the reflect a homogenous group of individuals. The generalisability of the studies is therefore limited and must be interpreted with caution, as they do not necessarily reflect the experiences of women in the UK generally.

**Table 5.**

*Table showing key features of the study*

| Author | Location | Participants | Study aim | Methodology |
|---|---|---|---|---|
| Ballard, Lowton & Wright (2006) | Southeast of England | n=32 | To investigate possible reasons for a delayed diagnosis of endometriosis and examine the impact that this has on women's experiences. | Semi-structured interviews |
| Clark (2012) | UK wide | n=13 | To examine the experiences of women with a surgical diagnosis of endometriosis. | Semi-structured interviews |
| Denny & Mann (2007) | Midlands | n=30 | To understand the impact of dyspareunia on women with endometriosis. | Semi-structured interviews |
| Denny & Mann (2008) | Midlands | n=30 | To explore the experience of women with endometriosis in the primary care setting. | Semi-structured interviews |
| Denny (2004) | UK Wide | n=15 | To explore women's experiences of living with endometriosis. | Semi-structured interviews |
| Denny (2009) | Midlands | n=30 | To explore women's experience of living with endometriosis over 1 year. | Semi-structured interviews |
| Drabble et al., (2021) | Northeast of England | n=20 | To describe the complexity and diversity of endometriosis-related pain from the perspective of the women experiencing it. | Semi-structured interviews |
| Grogan, Turley & Cole (2018) | UK Wide | n=34 | To understand women's experiences of endometriosis and its impact on their lives and relationships. | Open-ended questionnaires |
| Grogan, Turley & Cole (2021) | UK wide | n=34 | To examine constructions of identity in endometriosis and potential barriers to identity reappraisal. | Open-ended questionnaires |
| Harpur (2023) | UK Wide | n=11 | To understand the experience of women who have accessed psychological care for support with their endometriosis. | Semi-structured interviews |
| Jones, Jenkins & Kennedy (2004) | Oxford | n=24 | To identify and understand the areas of patients' lives that are affected by endometriosis. | Semi-structured interviews |
| Karavadra et al., (2025) | East of England | n=15 | To explore experiences of diagnosis in women with confirmed endometriosis. | Semi-structured interviews |
| Law et al., (2025) | Uk wide | n=44 | To explore the impact of endometriosis on women and their male partners | Semi-structured interviews |

**Table 5 continued.**

*Table showing key features of the study continued.*

| Author | Location | Participants | Study aim | Methodology |
|---|---|---|---|---|
| Taylor (2024) | UK wide | n=8 | To explore Black women's experiences of getting a diagnosis of endometriosis within the UK. | Semi-structured interviews |
| Varney (2022) | UK Wide | n=15 | To explore women's perceptions of their experiences of accessing and receiving psychological and emotional support. | Semi-structured interviews |
| Williams et al., (2025) | UK Wide | n=16 | To enquire into women's experience of painful endometriosis. | Open interviews |
| Wren & Mercer (2022) | UK Wide | n=9 | To explore young women's experiences of a diagnosis, to gain a better understanding of the impact of this process and the role and importance of support structures. | Semi-structured interviews |

## Understanding key concepts and categories

### *Diagnostic and Healthcare Challenges*

***Prolonged diagnostic journey.*** A recurrent theme across the reviewed studies was the prolonged and often distressing diagnostic journey experienced by women with endometriosis (WWE). This process was characterised by years of misdiagnosis, repeated consultations, and the normalisation of symptoms (Ballard, Lowton, & Wright, 2006; Denny, 2004; Denny & Mann, 2008; Wren & Mercer, 2022). Many participants reported being told their pain was "normal" or psychological in nature, leading to self-doubt and delayed help-seeking (Denny, 2004; Denny & Mann, 2008). Wren and Mercer (2022) highlighted that younger women were particularly vulnerable to "age-based dismissal," as clinicians often attributed severe menstrual symptoms to puberty rather than possible pathology. The emotional impact of this delay was significant. Women described feelings of frustration, invalidation, and isolation, with diagnosis providing long-awaited validation of their suffering (Denny, 2009; Wren & Mercer, 2022). Taylor (2024) further identified that Black women faced compounded barriers, as racialised assumptions about pain tolerance contributed to longer diagnostic delays and deeper mistrust in healthcare systems. Systemic shortcomings such as limited specialist training, fragmented referral pathways, and lengthy waiting times further exacerbated these challenges (Ballard et al., 2006; Varney, 2022). As a result, many women became self-advocates, seeking private consultations or self-educating to prompt diagnosis (Wren & Mercer, 2022).

***Dismissal and minimisation of symptoms.*** A pervasive theme across the reviewed literature was the systematic dismissal and minimisation of women's symptoms by healthcare professionals. Women frequently reported that their pain and distress were trivialised or attributed to psychological or emotional causes (Denny, 2004; Denny & Mann, 2008; Ballard,

Lowton, & Wright, 2006). This dismissal often began at the point of first consultation, where menstrual pain was described as "normal" or an exaggeration, reinforcing societal narratives that normalise women's suffering (Denny, 2009). Such interactions eroded trust and confidence in medical professionals, leading many women to internalise blame or question the legitimacy of their symptoms (Varney, 2022). Taylor (2024) further demonstrated that racialised and gendered stereotypes intensified this pattern, with Black women experiencing heightened disbelief and under-treatment, describing their journey as a "fight" or "battle".

***Communication barriers and health-seeking behaviour.*** Communication barriers emerged as a critical factor shaping how women navigated healthcare and sought help for endometriosis symptoms. Many participants described struggling to articulate the complexity of their pain within medical consultations, finding that language often failed to capture the severity, variability, or emotional toll of their experiences (Drabble et al., 2021; de C. Williams, Azadi, & McGrigor, 2022). This communication gap frequently led to misinterpretation by clinicians and contributed to feelings of frustration and misunderstanding. Poor communication also influenced health-seeking behaviour, as repeated invalidation or dismissal prompted women to delay seeking further medical advice or disengage from healthcare altogether (Varney, 2022; Wren & Mercer, 2022). For some, this disengagement stemmed from a lack of trust in clinical expertise, particularly when pain was minimised or psychosomatic explanations were imposed (Harpur, 2023). Conversely, others responded by intensifying self-advocacy, conducting their own research, and entering consultations more assertively to secure appropriate referrals (Taylor, 2024). Participants also reported difficulties discussing intimate symptoms, such as dyspareunia or infertility, which further limited open dialogue and reduced the likelihood of timely intervention (Denny, 2007).

***Interactions with healthcare systems/access to care.*** Women's interactions with healthcare systems were characterised by fragmented services, inadequate specialist access,

and inconsistent care pathways, all of which compounded delays in diagnosis and treatment. Several studies described how women were referred repeatedly between primary and secondary care without resolution, reflecting systemic inefficiencies and a lack of coordinated management (Ballard, Lowton, & Wright, 2006; Denny & Mann, 2008; Harpur, 2023). Limited clinician knowledge of endometriosis often resulted in inappropriate treatments or referrals, forcing women to navigate the system independently and advocate for specialist input (Varney, 2022; Wren & Mercer, 2022, Clark, 2012; Jones, Jenkins & Kennedy, 2004). Access to care was also shaped by socioeconomic and racial disparities.

### *Physical and Symptom Experience*

***Multifaceted pain experiences.*** Pain was consistently described as a complex, multidimensional experience that extended beyond physical sensations to encompass emotional, cognitive, and social dimensions. Across studies, women characterised endometriosis-related pain as unpredictable, debilitating, and resistant to conventional treatments (Drabble et al., 2021; de C. Williams, Azadi, & McGrigor, 2022; Law et al., 2024). Rather than a singular symptom, pain was portrayed as a constellation of experiences, including chronic pelvic pain, dysmenorrhea, dyspareunia, and fatigue, that fluctuated in intensity and impact (Denny, 2007; Drabble et al., 2021). Participants frequently described their pain as invisible yet life-defining, influencing their physical functioning, emotional stability, and social participation.

***Sexual health and intimacy.*** Sexual health and intimacy emerged as profoundly affected areas of life for WWE. Painful intercourse (dyspareunia) was frequently reported as one of the most distressing symptoms, significantly influencing both physical and emotional well-being (Denny, 2007; Denny, 2009; Law et al., 2025). Women described experiences of anticipatory fear and avoidance of intimacy, stemming from the unpredictability of pain during

sexual activity (de C. Williams, Azadi, & McGrigor, 2022; Law et al., 2025). This often led to feelings of guilt, frustration, and diminished sexual confidence, with many reporting strain in romantic relationships and difficulty communicating sexual needs (Denny, 2007; Varney, 2022; Law et al., 2025). The impact of dyspareunia extended beyond physical discomfort, challenging women's sense of femininity, desirability, and identity (Denny, 2009). Partners' reactions varied from understanding and empathy to frustration, reflecting how endometriosis redefined relational dynamics and intimacy (Drabble et al., 2021). Furthermore, women expressed that clinical consultations often neglected the discussion of sexual health, reinforcing feelings of shame and isolation (Varney, 2022).

***Fertility and reproductive concerns.*** Concerns regarding fertility and reproductive health were prominent across the reviewed studies, often intersecting with physical, emotional, and relational experiences. Women frequently reported anxiety about their ability to conceive, particularly when diagnosis was delayed, and pain or endometriotic lesions raised uncertainty regarding ovarian function and reproductive potential (Ballard, Lowton, & Wright, 2006; Denny, 2009; Wren & Mercer, 2022). The literature highlights that these concerns were not limited to future planning but affected identity and self-concept, with many women experiencing distress related to the perceived loss of normal reproductive function (Karavadra et al., 2025; Drabble et al., 2021). Delayed diagnosis amplified emotional strain, as prolonged uncertainty and inconsistent medical advice left women feeling powerless and anxious about long-term fertility outcomes (Denny & Mann, 2008; Varney, 2022).

### *Psychosocial Impact*

***Emotional and psychological distress.*** Living with endometriosis was consistently associated with significant emotional and psychological distress, encompassing anxiety, depression, frustration, and feelings of isolation. Women described the chronic and

unpredictable nature of pain as a major contributor to emotional strain, disrupting daily routines and limiting participation in work, education, and social activities (Denny, 2009; Drabble, Long, Alele, & O'Cathain, 2021; Williams, Azadi, & McGrigor, 2022; Law et al., 2025). The cumulative effect of repeated dismissal, delayed diagnosis, and inadequate clinical support further exacerbated distress, fostering feelings of helplessness and diminished self-worth (Wren & Mercer, 2022; Harpur, 2023). Several studies highlighted the impact of endometriosis on identity and sense of normality, particularly for younger women navigating adolescence and early adulthood. Participants reported that the condition forced them to renegotiate personal, social, and occupational roles, often feeling different or excluded from peers (Karavadra et al., 2025; Grogan, 2018). Emotional distress was also intensified by worries about fertility, sexual health, and long-term prognosis, contributing to pervasive uncertainty (Ballard, Lowton, & Wright, 2006; Varney, 2022).

***Impact on daily life and identity.*** Endometriosis was consistently reported to have profound effects on women's daily functioning and sense of identity. Participants described chronic pain, fatigue, and other symptoms as disruptive to education, employment, household responsibilities, and social participation, often necessitating adaptations or withdrawal from routine activities (Drabble, Long, Alele, & O'Cathain, 2021; Williams, Azadi, & McGrigor, 2022; Denny, 2009). These disruptions extended beyond practical limitations, influencing how women perceived themselves and their capabilities. Many reported a sense of loss of normality, feeling that their lives were constrained by a condition that was poorly understood or acknowledged by others (Karavadra et al., 2025; Wren & Mercer, 2022). It also affected self-identity and social roles, particularly for young women navigating adolescence or early adulthood. Participants described feeling different from peers, experiencing diminished confidence, and confronting challenges to their sense of femininity and bodily autonomy (Grogan, Turley & Cole, 2018; 2021; Varney, 2022). For some, repeated medical invalidation

and the need to manage ongoing symptoms reinforced a perception of being "unreliable" or "broken," further influencing social and professional engagement (Denny, 2004; Taylor, 2024).

***Stigma, cultural, and societal influences.*** Women's experiences of endometriosis were often shaped by societal attitudes, cultural norms, and stigma surrounding menstruation, chronic pain, and reproductive health. Several studies highlighted that menstrual pain is frequently minimised or silenced in broader culture, leading women to feel that their symptoms were abnormal or shameful (Grogan, Turley & Cole, 2018; Denny, 2004; Wren & Mercer, 2022). This societal minimisation reinforced internalised stigma, with participants reporting self-blame, guilt, and reluctance to discuss symptoms with peers, family, or healthcare professionals (Varney, 2022; Harpur, 2023; Grogan, Turley & Cole, 2021).

### *Coping and Self- Advocacy*

***Reliance on support networks and peer communities.*** Across the literature, WWE frequently relied on support networks and peer communities to manage the physical, emotional, and practical challenges associated with the condition. Family, friends, and intimate partners provided emotional support, helped with daily tasks, and validated women's experiences, particularly when formal healthcare systems failed to offer adequate guidance or understanding (Wren & Mercer, 2022; Harpur, 2023; Varney, 2022). Social support was identified as a critical buffer against the psychological burden of chronic pain, offering reassurance and reducing feelings of isolation (Grogan, 2018; Williams, Azadi, & McGrigor, 2022). Online platforms, including endometriosis-specific forums and social media groups, also played a key role in knowledge sharing and peer validation. Participants reported that engaging with peers who experienced similar symptoms enhanced their understanding of the condition, provided practical coping strategies, and fostered a sense of belonging (Drabble et al., 2021; Varney, 2022). However, some studies suggested that women engaging with support communities were

often those with less access to formal support, indicating that reliance on peer networks sometimes reflected gaps in healthcare provision (Grogan, 2018).

***Coping strategies and resilience.*** WWE demonstrated a range of coping strategies and resilience in response to the physical, emotional, and social challenges of the condition. Coping behaviours included symptom management, lifestyle adjustments, and seeking information independently to better understand their diagnosis and treatment options (de C. Williams, Azadi, & McGrigor, 2022; Wren & Mercer, 2022). Many participants developed strategies to manage pain fluctuations, such as pacing activities, planning around anticipated flare-ups, and using complementary or self-directed therapies (Drabble et al., 2021; Williams, Azadi, & McGrigor, 2022). Resilience was also evident in women's active advocacy for their own care, particularly in navigating healthcare systems and requesting referrals to specialists (Varney, 2022; Wren & Mercer, 2022). Engagement with peer communities and online support groups further reinforced resilience by providing emotional validation, practical advice, and opportunities to share coping strategies (Grogan, Turley & Cole, 2018; Harpur, 2023). However, it was noted that certain coping strategies mentioned may have been maladaptive, such as "getting on with things" and "suffering in silence" (Grogan, Turley & Cole, 2021).

***Navigating knowledge and self-advocacy.*** A prominent theme across the literature is women's active role in navigating medical knowledge and advocating for their own care. Due to delays in diagnosis, dismissal of symptoms, and inconsistent information from healthcare professionals, many participants sought out independent sources to understand endometriosis and its management (Varney, 2022; Wren & Mercer, 2022). This included researching medical literature, engaging with online forums, and connecting with support groups, enabling women to become "experts by experience" and to challenge clinical advice when necessary (Grogan, Turley & Cole, 2018; Drabble et al., 2021). Self-advocacy was closely tied to improving access

to care, with women requesting referrals, pursuing specialist consultations, or negotiating treatment plans aligned with their lived experience (Williams, Azadi, & McGrigor, 2022; Harpur, 2023). These behaviours reflected both resilience and frustration; while empowering, self-advocacy often required additional emotional labour in the context of systemic barriers and gendered assumptions about pain (Wren & Mercer, 2022).

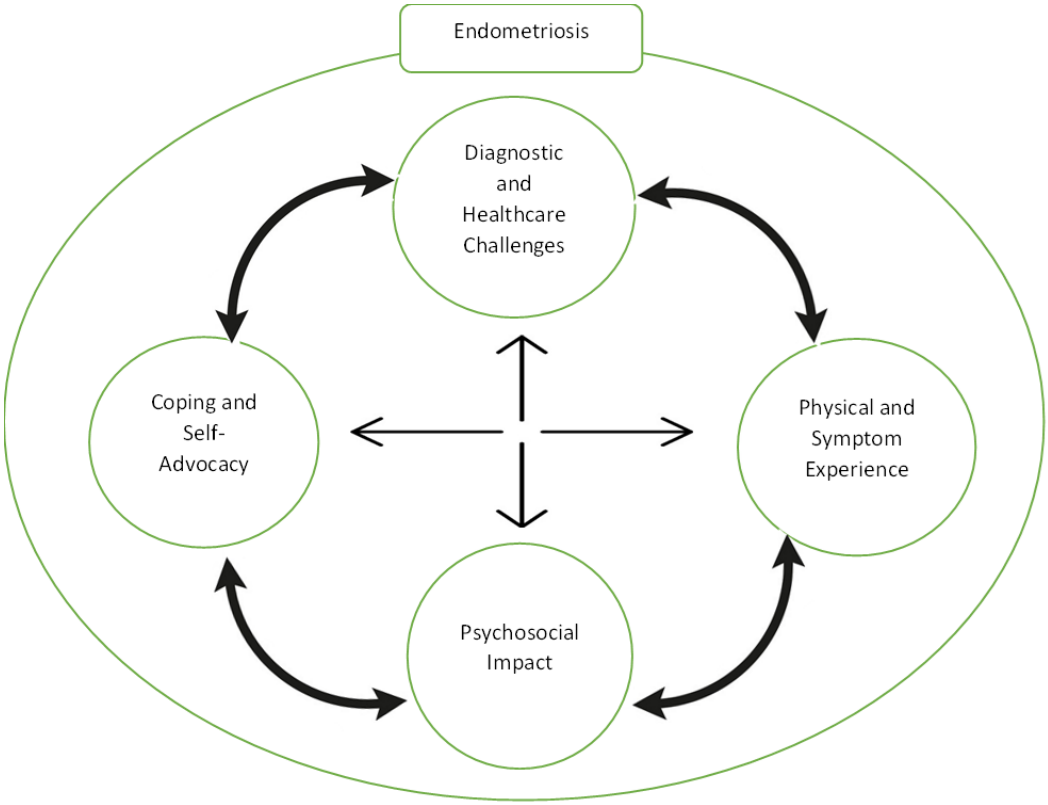
**Line of argument synthesis**

The process of line-of-argument synthesis, as outlined by Noblit and Hare (1988), involves developing a new, third-order conceptual understanding that integrates findings across multiple studies. In this meta-ethnography, second-order interpretations from each study were examined and compared, identifying overlapping, complementary, and contrasting insights into women's experiences of endometriosis. Through this process, recurring patterns were synthesised into four higher-order categories: diagnostic and healthcare challenges, physical and symptom experiences, psychosocial impact, and coping and self-advocacy.

The line-of-argument synthesis connected these categories to illustrate how experiences in one domain influence others. For example, diagnostic and healthcare challenges, such as delays, dismissal, and communication barriers, often exacerbate the psychosocial impact, contributing to emotional distress and identity disruption. Similarly, the complexity of physical and symptom experiences, including multifaceted pain, fertility concerns, and sexual health difficulties, shaped women's strategies for coping and self-advocacy, including reliance on peer networks, self-education, and proactive engagement with healthcare providers. By linking these categories, the synthesis provides a holistic conceptual model showing how systemic, social, and personal factors interact to shape the lived experience of endometriosis, offering a richer understanding than could be achieved by examining individual studies in isolation.

**Figure 3.**

*Line of argument synthesis: the multi-faceted experience of endometriosis*




## Discussion

Through the process of translation and synthesis, this meta-ethnographic review of the selected studies demonstrates that WWE in the UK face multiple, intersecting challenges throughout their healthcare journeys. The analysis revealed four overarching categories: diagnostic and healthcare challenges, physical and symptom experiences, psychosocial impact, and coping and self-advocacy. Together, these categories form a line-of-argument synthesis that represents the complex process WWE navigate as they seek diagnosis, treatment, and support. The findings suggest that these women encounter persistent barriers at every stage,

ranging from delays in diagnosis and inconsistent clinical care to limited treatment options and a lack of emotional and informational support. Collectively, the synthesis highlights how structural, interpersonal, and personal factors intertwine to shape the lived experience of endometriosis, often leaving women to manage their symptoms and wellbeing with minimal professional guidance.

These findings align closely with those reported by Pettersson and Berterö (2020), who conducted a meta-synthesis of literature published between 2000 and 2018. Their analysis identified three "fusions": insufficient knowledge, trivialising-just a woman's issue, and competence promotes health. While the terminology differs, the underlying concepts strongly echo the current synthesis. For example, the present category of diagnostic and healthcare challenges encompasses healthcare professionals' limited understanding of endometriosis, mirroring Pettersson and Berterö's (2020) concept of insufficient knowledge, which described clinicians' normalisation of symptoms, misdiagnosis, and reliance on outdated medical beliefs. Similarly, their fusion of trivialising resonates with the current synthesis' findings on psychosocial impact and coping and self-advocacy, where women reported feeling dismissed and left to seek alternative routes of care, often engaging in self-education and self-management strategies due to inadequate clinical support.

Pettersson and Berterö's (2020) final fusion, competence promotes health, captures how positive, informed interactions with healthcare providers fostered better health outcomes, an area less prominent in the current synthesis, likely reflecting the limited number of studies documenting such experiences. Nevertheless, both syntheses converge on the conclusion that women are frequently met with disbelief, minimisation, and insufficient care, resulting in prolonged suffering and emotional distress.

Consistent with ecological systems theory (Bronfenbrenner, 1979), the findings demonstrate how difficulties within healthcare settings extend beyond medical outcomes, influencing multiple aspects of women's lives. Inadequate healthcare can exacerbate symptoms, leading to increased work absences, financial strain, and reduced participation in social or familial activities. These interconnected effects highlight the systemic nature of endometriosis' impact, reinforcing the need for multidisciplinary, empathetic, and inclusive approaches to care that address not only the physical but also the social and emotional dimensions of women's experiences.

The findings of this synthesis suggest that, despite growing awareness of gender inequality within healthcare, women's experiences of endometriosis have not markedly improved in recent years. Persistent challenges such as delayed diagnosis, symptom dismissal, and inadequate treatment continue to dominate the narratives of women across studies. This stagnation may reflect the broader systemic disruptions in healthcare and research during the COVID-19 pandemic, which intensified pre-existing inequalities in service access and delivery. Consequently, while awareness has increased, tangible improvements in care and patient experience appear limited.

From a policy and practice perspective, several measures could strengthen support for WWE in the UK. One recurring theme within this synthesis was the insufficient knowledge and clinical competence of healthcare professionals, often contributing to misdiagnosis and delayed treatment (Ballard et al., 2006; Denny, 2009; Taylor, 2024). To address this, the General Medical Council (GMC) could mandate specialised training in women's health, including endometriosis, as part of continuing professional development to enhance diagnostic accuracy and patient-centred care. Current NICE (2017) guidelines already recommend a holistic, multidisciplinary approach that integrates physical, emotional, and social dimensions of care. However, adherence to these standards remains inconsistent across the UK. Ensuring

compliance and incorporating service-user involvement in guideline development, an approach supported by NHS England (2022) could foster a more collaborative understanding between patients and healthcare providers.

A critical gap identified in this synthesis concerns the lack of psychological care in existing clinical guidance, despite consistent evidence that endometriosis profoundly affects mental health and overall well-being (Varney, 2022; Harpur, 2023; Grogan, 2018). Future iterations of NICE and national women's health strategies should explicitly integrate psychological assessment and support pathways into routine endometriosis management. While the UK Government's Women's Health Strategy (DHSC, 2022) demonstrates a commitment to improving outcomes for women, its implementation may be hindered by systemic pressures on the NHS, including underfunding, workforce shortages, and long waiting times (Anderson et al., 2021).

To drive meaningful change, updated, UK-specific research is urgently required to capture diverse lived experiences and evaluate the real-world impact of current healthcare structures. Such evidence could inform resource allocation and policy development, ensuring that future reforms are both evidence-based and inclusive, ultimately improving diagnostic, therapeutic, and psychosocial outcomes for WWE.

**Limitations**

A limitation of this review is the inclusion of studies that relied on online questionnaires. As noted by O'Cathain and Thomas (2004), questionnaires may not provide the same richness or depth of data as in-person interviews or focus groups, potentially limiting the nuance captured in participants' experiences. This underscores the ongoing need for further research into endometriosis, particularly studies employing qualitative methods that allow for more detailed exploration of lived experiences.

Furthermore, meta-syntheses are generally conducted by multiple researchers to enhance rigor and reduce individual bias. In the current study, the synthesis was carried out by a single reviewer, which may have introduced subjectivity and increased the risk that interpretations reflect the reviewer's perspective rather than a consensus across multiple analysts.

This review includes only one study focusing specifically on a smaller subgroup of WWE (Taylor, 2024). While the synthesis provides valuable insight into the general experiences of WWE in the UK, treating all women as a homogenous group risks overlooking the unique experiences and challenges faced by specific populations. Factors such as cultural background, ethnicity, sexuality, and socioeconomic status may shape symptom perception, healthcare access, and coping strategies, highlighting the importance of considering diversity within research to ensure a more nuanced and representative understanding of lived experiences.

**Strengths**

This literature review makes an important contribution to understanding endometriosis within the UK context**.** While much of the existing literature has drawn on international samples, this review focuses specifically on UK-based studies, situating women's experiences within the realities of the NHS and related policy frameworks. This synthesis provides a nuanced account of how systemic, cultural, and personal factors intersect to shape women's healthcare journeys. It extends current knowledge by highlighting the persistence of diagnostic inequalities despite the publication of NICE (2017) guidelines, and by revealing gaps in psychological and holistic care provision within UK services. Moreover, this review emphasises the growing importance of self-advocacy and peer support among women navigating fragmented healthcare systems, underscoring a need for policy and service reform. Ultimately, this work advances understanding of endometriosis in the UK by providing an

evidence-based foundation for improving education, clinical practice, and women's health policy.

## Conclusion

This meta-ethnographic synthesis demonstrates the enduring and complex challenges faced by WWE in the UK. Despite growing awareness of women's health inequalities, findings reveal that diagnostic delays, inconsistent clinical care, and limited support continue to define women's experiences. Persistent barriers reflect broader systemic issues within UK healthcare, including insufficient clinician knowledge and limited access to multidisciplinary care. To address these shortcomings, greater emphasis must be placed on education and training for healthcare professionals, as well as policy reform that integrates psychological and social support within endometriosis management. Furthermore, future research should prioritise diverse and underrepresented voices to ensure that care provision reflects the full range of women's experiences.

The findings of this meta-ethnography informed both the focus and design of the empirical study. While the synthesis provided important insight into the experiences of women with endometriosis in the UK, most participants across the included studies were White, highlighting a lack of research exploring the experiences of women from ethnic minority backgrounds. This gap informed the decision to focus on South Asian women, especially due to the reported higher rates of endometriosis amongst this population. Additionally, recurring themes relating to diagnostic delays, communication with healthcare professionals, and self-advocacy influenced the development of the research questions and interview schedule, ensuring that key issues identified within the literature were explored in greater depth.

# Chapter Three: Methods

## Chapter Summary

This chapter outlines the methodological framework used to explore the subjective experiences of South Asian women living with endometriosis in the UK. Situated within a critical realist ontological and epistemological position and informed by a post-colonial feminist framework, the study employed a narrative approach to foreground participant voice and processes of meaning-making. Public and patient involvement informed key stages of the research, including study design, the interview process, and aspects of the analysis. Data were generated through open-ended narrative interviews with fourteen participants and analysed using thematic narrative analysis. Ongoing reflexive engagement, alongside regular supervision, supported the co-construction of meaning and ensured rigour and integrity throughout the analytic process.

## Philosophical Framework

Establishing the philosophical foundations of a study is essential for clarifying how the research is approached and how knowledge is produced (Creswell & Poth, 2016). Ontology and epistemology are key concepts that shape a researcher's understanding of reality and knowledge, and together they guide the selection of an appropriate methodological framework (Braun & Clarke, 2013). This process begins with identifying one's ontological position, which then informs the epistemological stance and ultimately the choice of research methods.

### *Ontology*

Ontology concerns the nature of reality, examining what exists, the types of entities that make up the world, and how these entities relate to one another (Crotty, 1998). It defines what researchers believe to be the subject of study and shapes their assumptions about what can be known or observed within that reality. Ontological positions can be understood along a continuum, with realism and relativism representing two opposing ends. Realism assumes that reality exists independently of human interpretation and can therefore be objectively observed and measured (Blaikie, 2007). In contrast, relativism proposes that reality is subjective and inseparable from individual perception, meaning that what is "real" depends on one's personal and contextual experience (Denzin & Lincoln, 2005; Guba & Lincoln, 2005).

In the context of endometriosis research, a realist ontology is reflected in the substantial quantitative evidence documenting measurable aspects of the condition, such as lesion presence, biomarkers, or patterns of symptom prevalence. These data suggest that certain features of endometriosis exist independently of how they are experienced, even though they may be interpreted in different ways. Conversely, a relativist ontology is demonstrated in research exploring the lived experiences of individuals with endometriosis, where symptoms,

pain, and the impact on daily life are understood as subjective, context-dependent, and shaped by personal meaning. Both ontological perspectives therefore offer valuable insights into the complex reality of endometriosis.

### *Epistemology*

Epistemology focuses on the nature of knowledge, including how knowledge is acquired, what justifies a belief as knowledge, and the limits of human understanding (Blaikie, 2007). It guides a researcher's approach to inquiry by influencing how they study the world and select appropriate methods. There are two main epistemological positions: positivism and interpretivism (Ormston et al., 2014). Positivism is rooted in the belief that reality is objective and measurable, with knowledge arising from empirical observation, quantification, and the search for general laws (Ryan, 2018). It suggests there is a single truth to be revealed and that there is no influence between the research and the participants (Denzin & Lincoln, 2011). In contrast, interpretivism emphasises the subjective nature of social reality, arguing that understanding human behaviour requires interpreting the meanings and experiences individuals attach to their actions (Alharahsheh & Pius, 2020). It suggests that there are multiple truths, which can change over time (Patton, 2015). While positivists aim for objectivity and hypothesis testing, interpretivists prioritise context, depth, and the socially constructed nature of meaning (Ryan, 2018). These divergent assumptions lead to different methodological approaches: positivist studies tend to use structured surveys and statistical analysis, whereas interpretivist research often employs qualitative methods, such as interviews, ethnography, or participant observation (Alharahsheh & Pius, 2020).

A positivist epistemology can be seen in endometriosis research that relies on objective measurement and statistical analysis, such as studies examining diagnostic accuracy, biological markers, or treatment effectiveness using quantitative data. In contrast, an interpretivist epistemology is reflected in research that seeks to understand the lived experiences of

individuals with endometriosis through their narratives, focusing on how they interpret and make sense of symptoms, pain, and the impact on daily life. These experiences are shaped not only by the participants' accounts but also through the researcher's interpretation, with both contributing to a shared understanding of what it means to live with endometriosis.

### *Methodology*

The ontological and epistemological stance directly shapes the choice of methodology. Methodology refers to the overall strategy used to investigate a research question (Silverman, 1993). Quantitative methodologies are typically aligned with a positivist paradigm, emphasising structured, hypothesis-driven inquiry, objective measurement, and researcher detachment from the phenomenon being studied (Hudson & Ozanne, 1988; Krauss, 2005). In contrast, research grounded in an interpretivist paradigm generally employs qualitative methodologies, which seek to understand and interpret the meanings individuals attribute to their experiences that are shaped by cultural, social, and temporal contexts (Black, 2006; Hudson & Ozanne, 1988).

Given the aim of the present study, "to explore the experiences of South Asian women with endometriosis living in the UK", including how cultural norms, stigma, and healthcare interactions shape those experiences, obtaining an "objective" account of the condition is neither possible nor appropriate. Instead, a qualitative methodology was deemed most suitable for capturing the nuanced, context-dependent realities of endometriosis in this population.

### *Self-Reflexivity*

Reflexivity involves critically examining how the researcher's perspective, presence, and actions influence the qualitative research (Gouldner, 1971). It is both a concept and a practice (Dowling, 2006). Conceptually, reflexivity requires self-awareness of how my personal experiences, values, and assumptions shape the research process (Lambert et al.,

2010). It also acknowledges that researchers are embedded within the social worlds they study and cannot remain entirely separate from participants (Ackerly & True, 2010; Shaffir & Stebbins, 1991). As a process, reflexivity involves continuous reflection on how my social positioning, cultural background, and experiences influence data collection, interpretation, and interactions with participants (Hesse-Biber, 2007; Parahoo, 2006). In this study, practising reflexivity is essential for making explicit the co-constructed nature of knowledge and for capturing the diverse, context-dependent experiences of South Asian women living with endometriosis (Jootun et al., 2009).

I am a twenty-nine-year-old South Asian woman with a diagnosis of endometriosis, adenomyosis and polycystic-ovarian syndrome (PCOS). I also have other health conditions, such as asthma. My personal history inevitably shapes the lens through which I approach this research. My parents divorced when I was five, and I grew up between two households with differing relationships to South Asian culture. My father, who spent his early childhood in Pakistan before moving to England, remains closely connected to his cultural and religious community. In contrast, my mother, born and raised in the UK, no longer practises the Sikh faith she grew up with and is not actively part of a South Asian community. My upbringing, therefore, consisted of both British values and norms, as well as the influences of Pakistani norms and culture. These contrasting cultural environments influenced how I learned to talk (or not talk) about my body and gynaecological health. This positioning may also shape how I listen to and interpret participants' accounts, particularly where experiences of cultural silence, modesty, or stigma around reproductive health are described. At the same time, sharing aspects of a South Asian cultural background may facilitate rapport with participants, while also requiring careful reflexive awareness to avoid assuming shared meanings or experiences.

From the onset of my first period at age ten, discussions about menstruation and later gynaecological symptoms were primarily navigated through my mother or stepmother. With

my father, these topics felt uncomfortable and were often avoided or spoken about indirectly; I sensed both his discomfort and my own feelings of embarrassment. Contrastingly, when discussing other health conditions such as my asthma or his autoimmune condition, conversations were open, although still often matter-of-fact and discussed through a medical rather than emotional lens. As my gynaecological symptoms intensified during adolescence and adulthood, leading to numerous medical appointments, I increasingly learned to articulate my experiences clearly to healthcare professionals and supportive individuals in my life. I feel this is partly due to growing personal confidence, and partly to wider societal shifts that have encouraged more open conversations about women's health. Yet even now, when speaking with my father, I notice myself withholding details, which I feel is shaped by cultural expectations surrounding privacy, modesty, and gendered norms. These experiences have also shaped my awareness of the ways in which cultural norms may influence how comfortably individuals discuss gynaecological health, particularly in relation to gendered family dynamics. As a researcher, this awareness may make me particularly attentive to moments in participants' accounts where topics are spoken about indirectly, minimised, or framed through notions of modesty or privacy. At the same time, my own experiences of learning to advocate for myself within healthcare settings may shape how I interpret narratives around help-seeking and communication with professionals, highlighting the importance of remaining reflexive about the assumptions I bring to the analysis.

Reflecting on these experiences, I recognise how my ability to advocate for myself within medical settings was facilitated by being raised, in part, by a mother who communicates directly and values independence. I am also aware that the narrative I construct about endometriosis is shaped by my social context, cultural background, and the audience to whom I am speaking. Acknowledging these influences is central to my reflexive position as a researcher, as they inform both my interest in this topic and my sensitivity to the experiences

of other South Asian women navigating endometriosis within similarly complex cultural landscapes.

I recognise that both my own worldview and those of the participants are shaped by broader social, historical, and relational contexts (Creswell & Poth, 2016). At the same time, I am aware that I cannot claim complete understanding of participants' lived experiences. I hope to provide space for their voices to be foregrounded and for their individual stories to be represented as authentically as possible.

My personal and professional background has made me acutely aware of disparities within healthcare systems, which has motivated my interest in this topic. As a trainee clinical psychologist, I also acknowledge the privilege and access that my position affords me in carrying out this work. Others, who may have valuable insights or lived experience, may not hold the same institutional power or resources to pursue such research. By articulating these reflections openly, I aim to enhance transparency, invite critique, and contribute responsibly to the development of knowledge in this area (Cohen et al., 2017).

**Research Paradigm**

This research adopts a critical realist epistemological and ontological stance. Critical realism suggests that reality exists independently of human perception, but our understanding of that reality is always partial, mediated through social, cultural, and linguistic practices (Bhaskar, 1978; Archer et al., 2016). It distinguishes between the real (underlying structures and mechanisms), the actual (events they generate), and the empirical (experiences of those events), allowing researchers to examine how both material and social forces shape health conditions. Within this framework, biological processes such as the inflammatory and hormonal mechanisms underlying endometriosis are understood as real, causal features of the world. At the same time, critical realism recognises that how these biological processes are

interpreted, responded to, and embedded within healthcare systems is shaped by social structures, cultural norms, and relational dynamics (Danermark et al., 2002).

This approach is well-suited to researching endometriosis in women of South Asian heritage because it accommodates both the biological reality of the condition and the social contexts that influence its recognition and management. While endometriosis arises from physiological mechanisms, the pathways through which women experience symptoms, seek help, and receive care are shaped by cultural expectations surrounding menstruation, gender roles, and medical authority (Ahuja & Maninder, 2016; Wilson et al., 2022). Critical realism facilitates an examination of how deeply ingrained cultural norms, such as silence surrounding reproductive health or expectations of endurance, intersect with healthcare structures to limit women's ability to articulate symptoms or access timely diagnosis (Choudhary & Nagar, 2023). Therefore, rather than treating experience as purely constructed, critical realism provides a lens for examining how biological, social, and cultural mechanisms operate together to shape women's lived experiences of endometriosis.

While this research adopts a critical realist approach, it also recognises that women's experiences are not universal and that the challenges of living with a health condition as a woman, and particularly as a woman from a racialised or formerly colonised background, are shaped by intersecting structures of gender, culture, and power. Feminist theory seeks to bring attention to social problems and challenges faced by women. It focuses on various key areas, including but not limited to discrimination based on sex and gender, objectification, economic inequality, power dynamics, gender roles, and stereotypes (Butler, 1990; Beauvoir, 1949; Young, 2005). The overarching goal is to analyse, critique, and ultimately work towards addressing and rectifying these issues within society. The feminist epistemology has widely been criticised as it is steeped in "whiteness" and takes on a westernised viewpoint, as it assumes that the experiences and struggles of white middle-class women in the West are

representative of all women's experiences (Hooks, 2015). PCF suggests that Western feminism ignores or misrepresents the realities and experiences of women in the global south (Mohanty, 1988). PCF draws on intersectionality research suggesting that gender cannot be understood separately from other factors such as race, class, ethnicity, and colonial history (Narayan et al., 2007). It highlights how different forms of oppression intersect and shape the experiences of women differently across different contexts. PCF strives to decolonise knowledge and research by challenging the predominant white Western discourse. It suggests that one way to do this is by incorporating indigenous and local forms of knowledge and giving a platform to marginalised and oppressed voices (Smith, 2021; Bhambra, 2014).

Working within a PCF framework requires recognising how colonial histories, racialised power structures, and gendered inequalities shape both the lived experiences of racialised groups and the processes through which knowledge is produced. PCF highlights the need to think about how knowledge is produced and who it is produced for. This approach challenges universal, Western-centred assumptions and instead foregrounds context-specific, culturally situated meanings (Mohanty, 2003). To work within a PCF framework, Manning (2016) emphasises that research must actively resist extractive practices by centring the agency, narratives, and interpretations of those who have been historically silenced. This involves treating participants not as subjects of inquiry but as co-producers of knowledge and engaging them collaboratively throughout the research process where possible, as well as communities and organisations in the work. Such work also requires sustained reflexivity, with researchers critically examining their own positionality, assumptions, and potential complicity in reproducing colonial logics (Swadener & Mutua, 2008). By embedding reflexive, participatory, and contextually grounded practices, a PCF framework enables research that is ethically attentive, culturally responsive, and oriented toward social justice. Therefore, whilst this research adopts a critical realist epistemology, it strives to work within a PCF framework. To

support this approach, participants were involved in co-constructing aspects of the research where possible, including contributing to the summarisation of their narratives. An expert-by-experience from a South Asian background, with connections to relevant community organisations, was also recruited to inform the research. In addition, the supervisory team included a supervisor from a South Asian background. A reflective journal was maintained throughout the project, with reflexive insights incorporated into the research to ensure transparency.

While qualitative approaches such as Grounded Theory and Interpretative Phenomenological Analysis (IPA) offer valuable analytic frameworks, they were not best aligned with the aims of this study. Grounded Theory (Charmaz, 2006) seeks to generate theoretical models through systematic comparative coding but is less suited to research that prioritises subjective meaning-making and the preservation of individual voices. Similarly, IPA (Smith et al., 2021) provides rich insight into lived experience, yet its analytic procedures typically fragment data into thematic categories and do not attend to the construction of stories over time. In contrast, narrative approaches recognise that personal accounts must be examined in ways that reflect the lived realities of storytellers (Frank, 1995). This is particularly important for this research as South Asian women with endometriosis will have experiences shaped by a multitude of factors, such as pain, stigma, shifting identities, and culturally situated expectations. Schiff (2013) suggested that narrative psychology is uniquely positioned to enhance understanding of individuals within their social and cultural contexts, setting it apart from mainstream psychological approaches. A narrative analytic approach maintains the integrity of the whole story, exploring not only what is said but how it is told, including narrative structure, temporal shifts, disrupted coherence, and metaphorical language (Riessman, 2008; Frank, 2010). This enables the analysis to capture changes in understanding across time, such as reinterpretations of pre-diagnostic experiences once a diagnosis has been

received, and to treat seeming contradictions or non-linear accounts as meaningful elements of the narrative rather than deviations. By foregrounding meaning-making, context, relationality, and cultural positioning, narrative analysis honours both the individuality of participants' experiences and the broader social and cultural patterns that shape them, making it an approach well aligned with the epistemological and ontological stance of this research.

### *Narrative Analysis*

This study employed thematic narrative analysis (TNA), as outlined by Riessman (2008). Riessman (2008) characterised a story as a chain of events connected by the speaker, while noting that the terms “story” and “narrative” are often used interchangeably. Narrative analysis is used to gain a deeper understanding of the meaning individuals attribute to their experiences (Stephens & Breheny, 2013). Because narrative approaches foreground lived experience, subjective meaning, and sense-making over time (Andrews et al., 2013), they are particularly suited to research with racialised groups.

Narrative methods have been identified as particularly valuable in health research due to their emphasis on context, complexity, and the preservation of meaning in participants’ accounts, making them especially suitable for intersectional and underrepresented populations (Chadwick, 2017). Importantly, narrative approaches are also widely used in evidence synthesis and applied health research where study populations and contexts are heterogeneous. For example, narrative synthesis has been employed in systematic reviews of chronic pain management and self-management interventions to integrate findings across diverse study designs, populations, and healthcare settings (Aspinall et al., 2019; Nicholas et al., 2019). This demonstrates the utility of narrative approaches in bringing together complex and varied evidence while retaining contextual richness. Narrative approaches have also been applied in qualitative health research on endometriosis, further supporting their suitability for exploring complex and multifaceted healthcare experiences (Bergen et al., 2023). Taken together, this

body of work supports the appropriateness of narrative methods for the present study, particularly given the variability and complexity of participants' diagnostic and healthcare experiences.

Contemporary narrative analysis reflects Dilthey's inductive and interpretive vision, drawing on hermeneutics to uncover explicit and implicit meanings within texts (Hill & Knox, 2021; Josselson, 2004). Narrative analysis recognises that stories are shaped within social and historical contexts and constructed for particular audiences, making it suited to the critical realist approach of the study (Hill & Knox, 2021). Critical realism allows the research to consider the underlying social and structural mechanisms that shape women's health experiences, while narrative analysis foregrounds participants' own accounts and meaning-making. Combining these approaches enables the study to situate personal stories within broader historical, cultural, and systemic contexts, balancing the richness of individual narratives with attention to structural factors influencing diagnosis, care, and understanding of the condition. Tensions between the approaches are acknowledged, including the challenge of reconciling narrative subjectivity with the realist aim of identifying underlying mechanisms, and the balance between particularity of individual stories and the search for broader explanatory patterns.

Riessman (2003) emphasised that narrative analysis involves two interpretive layers: first, understanding the meaning that individuals attribute to their experiences, and second, the researcher's interpretation of that meaning. Importantly, the meaning of a story can vary depending on the context in which it is shared (Wong & Breheny, 2018). Unlike other qualitative methods, narrative analysis attends closely to how events are sequenced and how language is used to communicate meaning (Riessman, 2008).

To contextualise narrative levels, Murray (2000) identified four domains: personal, interpersonal, positional, and ideological, though these have since been streamlined into three interconnected levels: personal stories, interpersonal co-construction, and social narratives (Wong & Breheny, 2018; Stephens & Breheny, 2013). Personal narratives organise experiences over time and space and reflect how individuals present themselves to others. Interpersonal stories are shaped through interaction with an audience, while social narratives situate individual experiences within broader cultural and societal frameworks. Narrative analysis also includes two broad analytic traditions: structural approaches focusing on plot, character, and sequence, and hermeneutic approaches emphasising interpretation and reflection (Hinchman & Hinchman, 1997).

Riessman (2008) outlined three primary analytic approaches: thematic, structural, and dialogical. TNA focuses on the content of stories; structural analysis examines how stories are told; and dialogical analysis attends to the relational and contextual dynamics shaping the narrative. In this study, analysis was primarily thematic, while remaining attentive to structural and interpersonal features of the narratives (Wong & Breheny, 2018).

**Research Design**

The focus of this research was to offer a space to South Asian women with endometriosis to share their experiences of obtaining a diagnosis and their experiences related to this. The study therefore used a qualitative design, and data were collected during in-depth semi-structured interviews. Qualitative research offers a deeper understanding of a phenomenon, especially in areas where existing evidence is scarce (Dixon-Woods et al., 2005). The interviews utilised open-ended questions to explore and follow each participant's journey from the onset of symptoms to receiving a diagnosis and support. This approach was employed to elicit richer responses, which are essential for narrative analysis (Riessman, 2008). The

design was also informed by a PCF epistemology, thereby foregrounding the research in women's stories (Smith, 2021).

***Public Patient Involvement (PPI)***

More recently, the value of using experts by experience in research has been highlighted (Domecq et al., 2014). Incorporating individuals with first-hand experience into the research process brings several benefits, such as enhanced recruitment and retention in studies and improved communication of outcomes to the intended audience (Domecq et al., 2014). This involvement can be empowering, aiding individuals to derive meaning from challenging experiences (Patterson et al., 2014; Simpson et al., 2014). Gathering insights from individuals directly impacted by the topic helps to position the research in a way that amplifies the voices of those for whom the outcomes are most significant (Groot et al., 2020). Additionally, it amplifies the voices of those who may not historically have been given a platform. This is particularly crucial for research involving racialised communities, who have historically faced structural and systemic forms of power that work against them (Bell & Pahl, 2018; Burns et al., 2014).

Conducting research fully in partnership with experts by experience was beyond the scope of this doctoral thesis. However, the researcher acknowledged that to fully align with the principles of a PCF framework, it would be ideal to engage in co-production at every stage with individuals who have lived experience of racial trauma (Fleming et al., 2023; Manning, 2016). The following paragraphs outline this process.

Several endometriosis charities were approached to provide consultation for this research, but either no response was received, or guidance could not be offered due to ongoing projects. The researcher aimed to involve an expert by experience from a South Asian background with a diagnosis of endometriosis. An individual meeting these criteria, who also

had prior experience providing research consultation in women's health, was recruited. A contract was established to clarify roles and responsibilities (Appendix D), and the expert by experience was compensated £30 in vouchers per session over three sessions.

The first session focused on reviewing the interview schedule, recruitment strategies, potential recruitment challenges, and reflecting on appropriate language and terminology, leading to revisions to make questions more patient-centred. The second session addressed data analysis and the development of themes, fostering collaboration in interpreting findings. The final session considered dissemination strategies and how best to provide feedback to participants, ensuring their perspectives were represented in the reporting of outcomes. All sessions were used to reflect on the power dynamics between the researcher and participants. Changes and reflections from this process can be seen in Appendix E.

***Ethical considerations***

Ethical consent was obtained from the University of Essex Ethics Committee (Appendix F). The study was conducted in accordance with the British Psychological Society (BPS) Code of Ethics and Conduct (2018). Particular emphasis was placed on trust, power, and confidentiality, as these are especially critical when engaging with participants from racialised backgrounds (Cresswell & Poth, 2016).

Due to individuals from racialised backgrounds previously being excluded from research, there was the potential that participants would require more detailed information about the study and what participation would look like to decide whether to participate in the study (Rawlings & Bains, 2020). Participants were asked to review the information sheet before deciding whether they wished to participate, and an opportunity to ask questions was provided over e-mail or through a Microsoft Teams call. To uphold ethical standards, all participants were provided with a consent form, which they signed before being formally recruited into the

study. Participants were given the researchers' details to ensure they could get in contact should they have had any questions that came up after participation. Participants were informed of their right to withdraw from the study without any negative consequences.

This study aimed to explore experiences of endometriosis, which included experiences of healthcare, emotional-wellbeing and the impact on day-to-day life. It was recognised that this might have been a sensitive topic for some participants. There was a possibility that participants could become distressed, especially considering that previous research has found that endometriosis can affect individuals' emotional well-being (e.g., Bergen et al., 2023). Recognising that participants may have different relationships to discussing emotions and seeking support, interviews began with general, non-research questions to allow rapport and comfort to develop. The researcher also shared information about themselves and invited participants to ask questions, helping to foster a more open and trusting interview environment. Participants were checked in with throughout the interview, and if any signs of distress arose, they were asked if they needed to pause the interview or wished to take a break. At the end of their interviews, all participants were offered a debrief with the interviewer and given a debrief sheet outlining the contact details for various support organisations.

As the topic also had the potential to be emotionally challenging for the researcher, regular research supervision was undertaken to provide space for reflection, alongside engagement with a mentor for additional support.

### *Inclusion and Exclusion Criteria*

To be eligible to participate in the study, participants had to be over the age of 18, as this is the minimum age at which an individual can give informed consent. To ensure clarity regarding the experiences of women with endometriosis, participants needed to have a confirmed diagnosis of endometriosis by a medical professional (e.g. through laparoscopy or

MRI) rather than a suspected diagnosis. Participants with a diagnosis of endometriosis and other gynaecological health conditions, such as adenomyosis or polycystic ovaries, were included due to the high comorbidity of these conditions. Additionally, participants had to identify as South Asian[1], speak English, and reside within the UK. This exclusion criterion was applied due to the study's objective to influence health policy in the UK.

***Recruitment***

Drawing on insights from previous studies involving racialised participants, recruitment challenges were anticipated (Brown et al., 2014). Factors such as stigma, concerns about confidentiality, and a limited understanding of the research process posed significant obstacles (Brown et al., 2014). Therefore, it was crucial to present information clearly and transparently to participants, allowing ample opportunities for questions and emphasising the importance of consent and the ability to withdraw from the study. Additionally, participants were informed in the information sheet (Appendix G) that they were able to have their cameras off during the interview, should they wish to, allowing them to maintain their privacy. Research indicates that shame and stigma can surround menstruation and women's health in South Asian communities; privacy in their identities would allow them to speak more openly.

Participants were recruited using poster advertisements on social media (Instagram, Facebook and LinkedIn). It was originally intended that posters would also be distributed at specialist South Asian centres, such as Hindu Mandirs, Sikh temples, and Muslim mosques. However, due to the study reaching participant capacity after two weeks of being advertised, this step was not carried out. This will be explored further in the discussion chapter.

[1] This study defines South Asians as individuals with ancestral ties to Afghanistan, Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan, and Sri Lanka (APA, 2019). See Chapter One, page 10 for a further discussion.

***Procedure***

Participants who were interested in taking part in the study contacted the researcher directly by e-mail to express interest, ensuring voluntary participation. The lead researcher then screened participants to check that they met the inclusion criteria. This was done using a screening form that the researcher sent to participants to complete (Appendix H). At the same time, they were sent the study information sheet, so they could make an informed choice about whether they would like to participate. Once eligibility was confirmed, the researcher e-mailed participants asking them whether they would prefer to meet in person or online for the interview. All participants in the current study opted for online meetings. A meeting time was agreed upon, and participants were sent a Microsoft Teams link via email along with the consent form (Appendix I). Participants were informed that the consent form must be completed before the interview could take place and were given the option to complete it and send it to the lead researcher by e-mail, or to complete it with the lead researcher at the start of the call before their interview took place.

At the start of each Microsoft Teams call allocated for the interview, the interviewer reconfirmed participants' consent to take part in the research or filled in the consent form with participants by using the share screen function and reading through the consent form with them. Participants were given the opportunity to ask any questions about the research and the interview at this stage. The researcher took time to re-explain the research, including its purpose and the hopes for the research, to build rapport with the participants. Following this, the semi-structured interviews took place, which lasted between 60 to 100 minutes. Participants were given a chance to debrief with the lead researcher following the interview. At the end of each interview, the lead researcher re-informed participants that they would be sent their transcripts via email and asked whether they would like to make any changes. Some participants indicated that they did not wish to have their transcripts sent to them, and this was

noted down. Once the interview had finished, the researcher sent the participants a debrief sheet via email, which contained a list of organisations where they could seek support should they wish to.

Interviews were then transcribed by the lead researcher. Microsoft Teams provides an automatic transcript of each interview; however, the lead researcher went through each transcript while listening back to the audio recordings of the interview, checking that they were correct, and adding utterances. Interviews were pseudo-anonymised using participant numbers. Any information that could potentially compromise anonymity was redacted, including names, locations, hospitals, and health care professionals. Transcripts were then emailed to each participant, inviting feedback. This was done to further allow patient collaboration and to work PCF framework (Barei-Guyot, 2023). Reviewing transcripts was optional, and participants were informed they had two weeks to respond if they wished to comment. If the researcher had not heard from participants in this time frame, it was agreed that the researcher would take the transcript sent to them as the final version. One participant noted at interview stage they did not wish to be sent their transcript. Five replied with minor changes (word corrections). After changes requested by participants were made, the interview transcripts were completed and deemed ready for data analysis. Once transcripts were finalised, a summary of each participant's narrative was prepared by the researcher and shared with them for review. Participants were invited to suggest amendments to ensure accuracy and were also asked to select a pseudonym. Six participants engaged in this process, with most requesting no changes or minor changes (e.g. a few words). One participant identified part of her story as missing from the summary and sent across additional sentences that were more reflective of her experience.

***Data Storage***

Interview transcripts and audio recordings were saved on a laptop using a secure, password-protected hard drive. Transcripts were to be retained for five years to allow for possible journal publication or the development of practice guidelines. Audio recordings were to be kept for two years for review purposes and then deleted. Any printed interview materials or notes were stored in a lockable cupboard, accessible only to the researcher during data analysis and write-up. After this time, all physical documents were either cross-shredded or disposed of in a confidential waste bin to ensure personal data protection in line with GDPR requirements.

**Materials**

A topic guide was used in all interviews (Appendix J). It was developed with reference to the key experiential domains identified in Chapter Two meta-ethnography, alongside PPI input, to ensure continuity between the literature synthesis and the empirical study. A topic guide is a valuable tool in qualitative research, providing consistency and direction for the researcher in defining the scope of exploration necessary to address the research question within the chosen methodological approach (Patton, 2002). Unlike a fixed agenda, the guide allows the interviews to be shaped by the participants' own lines of inquiry. This was important as PCF emphasises the importance of giving participants room to speak and tell their story, meaning at times the interviewer need to give up their own power and let the participant take the lead (e.g. Reissman, 2008; Barei-Guyot, 2023). This approach enables the interviews to focus on areas of significance as identified by each participant, while still allowing the data to be synthesised for pattern and theme interpretation (Charmaz, 2002; Kallio et al., 2016). Additionally, the use of probes and follow-up questions enriched the depth of the interviews (Lingard & Kennedy, 2010).

**Sample Size**

The sample size of 14 participants was considered appropriate for this narrative qualitative study, in line with established qualitative methodology which prioritises depth, richness, and analytic adequacy over statistical representativeness. Sample adequacy was guided by the concept of information power, whereby fewer participants are required when the study aim is narrow, the sample is highly specific, and interviews are rich in relevant experiential detail (Malterud et al., 2016). In this study, participants shared sufficiently detailed and contextually embedded accounts of their diagnostic and healthcare experiences, allowing for in-depth narrative analysis. Recruitment continued until the point at which no new narrative patterns or interpretive insights were emerging within the data. Furthermore, a sample of this size is consistent with narrative and in-depth interview-based qualitative health research, where sample sizes typically range from approximately 10 to 20 participants depending on study aim and design (Guest, Bunce & Johnson, 2006). Together, these considerations support the adequacy of the final sample size for addressing the research objectives.

**Participants**

The study participants were 14 women between the ages of 20-60 years old, with a mean age of 32. All participants identified as being from a South Asian background and included individuals with Indian, Pakistani, Nepalese, and Bangladeshi heritage. Two participants chose not to specify their South Asian background. Participants' religious identities included Atheism, Islam, Hinduism and Christianity. Eight participants were born in the UK, and six were born elsewhere and migrated to the UK. Ten of the participants were married or had a partner, and three had children. Participants were from various locations across England, including locations in the North, South and Midlands. There were no participants from Northern Ireland, Scotland or Wales.

**Table 6.**

*Participant demographics and clinical characteristics*

| Variable | Number |
|---|---|
| Age | |
| 18-25 | 2 |
| 26-32 | 8 |
| 32-39 | 3 |
| >39 | 1 |
| Dependents | |
| Children | 2 |
| No children | 12 |
| Marital Status | |
| Married/ Partner | 10 |
| Single | 3 |
| Divorced | 1 |
| Year of diagnosis | |
| 2016 | 1 |
| 2019 | 1 |
| 2020 | 3 |
| 2021 | 2 |
| 2022 | 1 |
| 2023 | 1 |
| 2025 | 2 |
| Not disclosed | 3 |
| Religion | |
| Islam | 8 |
| Hindu | 3 |
| Christianity | 1 |
| Atheism | 2 |
| South Asian Background | |
| India | 5 |
| Pakistan | 4 |
| Bangladesh | 2 |
| Nepal | 1 |
| Multiple | 1 |
| Not disclosed | 1 |

**Data Analysis Procedure**

The analytic process began with verbatim transcription of all audio-recorded interviews, capturing pauses, hesitations, and emphasis. This allowed for close engagement with the data and supported familiarity with both thematic and structural elements of the stories (Riessman, 2008). Transcription was undertaken as soon as possible after each interview, and initial reflections were noted in the transcript margins to document early analytic impressions (Smith, 2016).

The next step involved indwelling, comparable to the immersion or familiarisation phase common to other qualitative methodologies. The researcher read and listened to each interview multiple times, annotating the transcripts and noting early patterns or striking passages. This stage helped orient the researcher to the participant as a storyteller rather than as a source of extractable information (Smith, 2016).

Following the process of indwelling, the researcher constructed an individual narrative summary for each participant, capturing the core events, meanings, and contextual influences within their accounts. These summaries were returned to participants for review, inviting feedback, clarification, and amendment to ensure that their experiences were represented accurately and authentically. Participant story summaries were used to preserve each individual's narrative, recognising that derived themes or typologies may not capture every participant's experience. This approach also aligns with a PCF framework by providing a platform for participants' voices and avoiding the silencing of individual stories within the research.

The researcher then moved to identifying stories within each transcript. Following Wong and Breheny (2018), stories were identified through markers such as references to time, place, characters, or shifts in narrative direction. In this research, characters included families,

partners, colleagues and healthcare professionals. Stories varied in length and complexity. Riessman's (1993) concepts of "entrance" and "exit" talk were used to locate story boundaries.

Once core narratives were identified, their structural characteristics were examined. The narratives were also considered in relation to personal, interpersonal, and social levels (Wong & Breheny, 2018) to contextualise individual meaning-making within broader relational and cultural conditions and the structure of the story was also considered (Gergen & Gergen, 1983).

Next, narrative themes and thematic relationships were developed. Although producing themes is not essential in narrative research, this study adopts a critical realist approach, and identifying themes allows for the exploration of underlying mechanisms, patterns, and shared experiences. This, in turn, helps to link participants' narratives to broader insights that can inform policy and practice. Following Smith's (2016) recommendations, this stage involved preserving the integrity of each story rather than fragmenting it through excessive coding. The researcher carefully read each transcript to identify recurring ideas, tensions, and narrative threads. Key sentences were highlighted, important phrases underlined, and salient words circled. Marginal notes captured both explicit content and underlying meanings. This process remained distinct from coding practices in other qualitative methods (e.g., Braun & Clarke, 2006; Glaser & Strauss, 1967), as the aim was to maintain narrative coherence rather than generate abstracted categories across cases.

Finally, individual cases were examined in relation to one another to identify narrative patterns and typologies, following Riessman (2008) and Järvinen and Mik-Meyer (2020). Narrative typologies (stories that share similar qualities or storytelling strategies, [Frank, 2012]) were used to highlight shared and divergent experiences across participants. Throughout the analytic process, methodological integrity was upheld through transparency about

researcher positioning and reflexivity regarding how interpretations were shaped (Levitt et al., 2016). This approach allows the study to highlight common structures or trajectories while preserving individual voices, and to link personal narratives to broader social and structural factors that can inform policy and practice. Narrative typologies are presented in the discussion rather than the results, as their development involved interpretive analysis by the researcher, whereas the results chapter prioritises foregrounding participants' voices and narratives. A sample of a transcript can be seen in Appendix JK.

## Quality Appraisal

The Critical Appraisal Skills Programme (CASP) qualitative checklist is a widely used framework for evaluating the rigour, credibility, and relevance of qualitative research (Critical Appraisal Skills Programme UK, 2018). Majid and Vanstone (2018) emphasise that appraisal tools such as CASP are particularly valuable in evidence synthesis as they assess transparency, methodological coherence, and reflexivity. This section critically appraises the current study exploring South Asian women's experiences of endometriosis in the UK using the CASP framework, reflecting on methodological strengths and limitations. The lead researcher carried out the review, and it was then checked with a supervisor. To mitigate subjectivity in the self-assessment, the researcher used the CASP scoring from the systematic review as a comparison point. As outlined in Chapter Three, the CASP scoring approach was adapted to enhance sensitivity within the appraisal process (Long et al., 2020).

**Table 7.**

*CASP scores*

| 1. Aims | 2. Qualitative Methodology | 3. Research Design | 4. Recruitment | 5. Data Collection | 6. Relationship | 7. Ethical Issues | 8. Data Analysis | 9. Findings | 10. Value | Total Score |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | 1 | 1 | 0.5 | 1 | 0.5 | 1 | 0.5 | 1 | 1 | 8.5 |

*Note: 1 indicates the criterion was met; 0.5 indicates the criterion was partially met or the required information was unclear or insufficient, and 0 indicates the criterion was not met.*

### *Clear Aim*

The study aimed to explore the experiences of South Asian women living in the UK with endometriosis, with particular attention to healthcare interactions, cultural influences, and diagnostic journeys. The research question was clearly articulated and justified by the underrepresentation of ethnically diverse populations in endometriosis research.

### *Appropriate Methodology*

A qualitative methodology was highly appropriate given the exploratory nature of the research question. Understanding culturally situated experiences of chronic illness requires attention to meaning-making, identity, and structural context, which are not adequately captured through quantitative methods.

### *Appropriate Research Design*

Narrative analysis was employed to explore how participants constructed and interpreted their endometriosis journeys. This design was appropriate given the emphasis on temporality, diagnostic delay, and culturally mediated illness narratives. Narrative analysis enabled attention to how participants positioned themselves within cultural expectations of femininity, pain tolerance, and family roles. This aligns well with both the research question and critical realist positioning.

### *Appropriate Recruitment Strategy*

Fourteen South Asian women in the UK were recruited via social media, a pragmatic approach that enabled access to a potentially marginalised group who may not be easily reached through clinical routes. However, this strategy may have introduced sampling bias, as participants engaged in online communities or those with more severe or negative healthcare

experiences may have been overrepresented, while individuals without digital access or English fluency may have been excluded. This limits transferability and potentially narrows the diversity captured within the broad and heterogeneous category of "South Asian." Nonetheless, a sample size of fourteen is appropriate for qualitative, depth-oriented narrative research.

### *Data Collection*

Data were collected through in-depth interviews, allowing participants to narrate their illness journeys in their own terms. This method is congruent with narrative analysis and supports exploration of temporality and identity construction. The use of open-ended prompts likely facilitated rich storytelling.

### *Reflexivity and Relationships*

The researcher engaged in reflexive journaling throughout the study. Reflexivity is particularly salient in this study, as the researcher shares both South Asian identity and lived experience of endometriosis with participants. This insider positioning likely enhanced rapport, trust, and cultural understanding. While positionality was acknowledged, greater critical interrogation of how lived experience influenced narrative interpretation would enhance confirmability.

### *Ethical Issues*

Ethical approval was obtained, informed consent secured, and confidentiality maintained. Given the cultural sensitivities surrounding menstruation and reproductive health within some South Asian communities, ethical sensitivity was particularly important. Additionally, all participants were paid for their participation.

### *Data Analysis Rigour*

Narrative analysis was conducted in alignment with the stated critical realist framework, attending carefully to story structure, temporality, and participant positioning, thereby moving beyond surface-level thematic categorisation. There was clear coherence between the epistemological stance and the analytic approach, with participant narratives used effectively to illustrate interpretive claims and situate individual experiences within broader sociocultural contexts. This strengthened the explanatory depth of the analysis by linking lived experience to underlying structural mechanisms. However, the rigour of the analytic process could have been enhanced through the incorporation of independent review or supervisory auditing.

### *Statement of Findings*

Findings were clearly presented and structured around key narrative patterns such as diagnostic delay, cultural silence around menstruation, healthcare dismissal, and identity negotiation. Participant excerpts were used effectively, enhancing authenticity and credibility.

### *Research Value*

This study makes an important contribution by centring the voices of South Asian women, a group significantly underrepresented in endometriosis research within the UK. It highlights how cultural norms, gendered expectations, and structural healthcare inequalities intersect to shape diagnostic experiences. The findings have implications for culturally competent healthcare provision, practitioner awareness of racialised diagnostic delay and inclusive reproductive health policy. While transferability is limited by recruitment via social media and the specific demographic focus, the depth of narrative insight enhances its conceptual and theoretical value.

***Overall Assessment***

Using the CASP framework, the study demonstrates moderate methodological rigour. It shows strengths in clarity of aims, appropriateness of methodology, and coherence of findings. However, limitations are evident in recruitment diversity and analytic transparency. Addressing these areas would enhance credibility and trustworthiness in future research.

# Chapter Four: Results

## Chapter Overview

This chapter presents the findings of the TNA, exploring how participants made sense of their experiences of endometriosis across their life course. TNA focuses on identifying recurring themes across participants' stories while preserving how experiences are narrated as meaningful, storied accounts. It attends both to what is told (shared patterns of experience) and how it is told (sequencing, positioning, and making sense of experiences over time). Rather than fragmenting accounts into isolated codes, the analysis attends to how stories were told, which experiences were foregrounded, and how participants positioned themselves, others, and healthcare systems within their narratives. It begins by describing each of the participants and summarising their stories, capturing how they described and made sense of their endometriosis experiences. Narrative themes are then presented, outlining recurring ideas, tensions, and narrative threads. The analysis is organised around six interrelated narrative themes, with narrative features discussed throughout. Narrative themes capture the overall shape and trajectories of participants' stories, highlighting recurring storylines and shared experiences across accounts. Narrative features are examined within these themes, attending to how stories are told, including structural, relational, and stylistic patterns that shape the construction, sequencing, and meaning of participants' experiences.

## Participant Story Summaries

It is important to first foreground the distinct ways in which each participant structured their story and articulated the interpersonal, intra-personal, and cultural contexts that shaped their experience. These introductory summaries aim to preserve the individuality and integrity of each participant's lived experience, reflecting the varied trajectories, meanings, and coping processes evident across accounts. Summaries were co-constructed with participants.

Participation in this stage was optional, and those who elected to engage in the co-construction process are indicated with an asterisk (*).

### *Zara*

Zara's endometriosis journey began in her teenage years and unfolded within a cultural context that framed women's health and menstruation as private and unspeakable. This cultural script contributed to feelings of shame and silence, delaying her ability to discuss her symptoms openly. Faith emerged as a key source of strength, helping her endure ongoing pain and uncertainty. Within her story, healthcare professionals occupy distinct narrative roles: her GP is positioned as a "villain," characterised by dismissal, a poor therapeutic relationship, and the use of cultural stereotypes (e.g., referring to "women of your background"), which contributed to self-doubt and negatively impacted her mental health. In contrast, her gynaecologist is constructed as a "hero," offering validation and a more positive, supportive care experience. Over time, Zara describes a shift toward greater confidence in speaking about her endometriosis and advocates for the creation of more spaces where individuals can share their stories. Pain relief remains a central concern, and she frames her journey as ongoing.

### *Angelie**

Angelie's endometriosis journey began in her teenage years, when she started her periods at age 14. From the outset, her periods were extremely heavy and painful. She recalled that no matter how she tried to manage them with sanitary products, she would still experience blood soaking through, at times running down her leg. The severity of her symptoms often left her bedbound for two to three days each month, and she recognised early on that her experiences were more intense than those of her peers. Standard painkillers were not sufficient to manage her pain.

She attended her GP regularly and was prescribed pain relief, but reported that little investigation was carried out into the underlying cause of her symptoms, often being told it was just a “painful period”. Her condition significantly impacted her university experience, as she was often unable to care for herself or participate socially during flare-ups, relying heavily on a friend for support.

Angelie was diagnosed with endometriosis in the late 1980s but described receiving no treatment following diagnosis. She continued to seek pain relief to manage ongoing symptoms and began researching the condition herself due to the limited information available in the UK at the time. In the 1990s, she sought private care and underwent laparoscopic surgery and laser treatment.

She spoke about the cultural pressure to have children, which affected her emotional well-being, despite having a supportive husband. She expressed concern about community perceptions, noting that within South Asian cultures, women are often blamed for difficulties with childbearing. She felt that women’s health is often not openly discussed in her community and highlighted the need for more accessible information in relevant languages.

Reflecting on her experience, Angelie felt that awareness of women’s health has improved over time, and she now speaks openly about endometriosis to support others. However, she recognised that challenges around diagnosis and treatment still remain.

***Sienna***

Sienna began experiencing symptoms of endometriosis before their teenage years. Over time, she consulted multiple GPs and tried various forms of contraception, but her symptoms were repeatedly dismissed and not believed. Her diagnosis came after she was placed on the cancer pathway, an experience that marked a significant turning point in her story. Following this, she sought private healthcare.

Within her narrative, the gynaecologist is described as a key positive figure (hero) who provided validation and support. Her story is non-linear, reflecting the ongoing and uncertain nature of living with endometriosis. She is currently awaiting further surgery, highlighting that her journey is still ongoing. Throughout her experience, Sienna emphasised the importance of her support system in helping her navigate her endometriosis journey.

***Aaliyah****

Aaliyah began experiencing symptoms of endometriosis before her teenage years and described growing fear and anxiety around her periods, due to becoming unwell from them each month. She missed a significant amount of school and was aware from an early age that her experiences were different from those of her peers. Although initial tests returned as normal, she later received a diagnosis through MRI, which led to some uncertainty about the diagnosis itself.

She reported trying multiple forms of hormonal medication to manage her symptoms. Within her family, periods were discussed factually and framed as a "women's issue," reflecting a cultural script that normalised menstruation while limiting emotional discussion. Humour was commonly used by both Aaliyah and her family as a coping strategy.

She reported heavy and painful periods, as well as bloating ("endo belly"), which negatively affected her self-esteem. Due to limited information available through formal healthcare channels, she turned to social media to better understand her condition. She also reflected on a tendency to "just get on with things" regarding her mental health, recognising that this approach sometimes prevented her from processing emotions fully. She described living with endometriosis as "climbing a mountain," emphasising both challenge and persistence. Presenting herself as solution-focused, she spoke about leaning into her faith as a way of making sense of her experiences and navigating her ongoing endometriosis journey.

***Ulima ****

Ulima began experiencing symptoms before her teenage years and described her periods as "hell," with severe pain causing frequent absences from school. She attended multiple medical appointments but was repeatedly dismissed and told that nothing was wrong, which led her to begin doubting her own experiences and losing trust in doctors. Endometriosis was first suggested to her by people in her personal life, before she was familiar with the condition herself.

Her symptoms continued into adulthood, affecting her ability to work due to extreme fatigue. Eventually, she left her job and changed career. Following her diagnosis, she chose to delay having children, fearing disappointment related to fertility. After feeling repeatedly "palmed off" by healthcare professionals, she described reaching a point where she stopped asking for help and instead told doctors that she had endometriosis. Unable to wait for NHS care, she sought a private diagnosis.

Ulima described "giving up on doctors" and becoming her "own doctor," managing her endometriosis through diet and non-Western approaches to health. She expressed a belief that many health issues are linked to gut health and preferred natural methods of managing symptoms. Within her family, periods had traditionally been treated as private, but she deliberately broke this cultural script, becoming open about women's health and positioning herself as someone others could turn to for support and advice.

Despite significant challenges, Ulima framed her experience of endometriosis in largely positive terms. She described becoming more knowledgeable about health and using this understanding to benefit her children's lives. Her husband and wider family were described as a strong and supportive network throughout her endometriosis journey.

***Yasmin ****

Yasmin lives with multiple gynaecological conditions and described her endometriosis journey as beginning in her late teenage years, when she experienced heavy and painful periods. Initially, she attributed these symptoms to PCOS, but questioned this when symptoms continued even outside of menstruation. Although she noticed that something was wrong as early as age 12, the use of hormonal contraception masked her symptoms.

She described navigating different cultural expectations within her family, noting that how openly she spoke about her health depended on which side of the family she was addressing. Periods were commonly framed as taboo and as a "women's problem".

Yasmin expressed anger and frustration about the lack of attention given to women's health compared to men's health, as well as a broader lack of accessible information about endometriosis. She described growing distrust in medical advice and feeling let down by both NHS and private healthcare providers, particularly in relation to treatment options, which she felt were limited due to her age. Comments from healthcare professionals about her weight contributed to feelings of self-consciousness.

Endometriosis was described as a dominant condition that "takes over," affecting her mood and ability to socialise. She reflected that she is still learning to manage the emotional impact of the condition. Her partner, who also lives with a long-term health condition, was described as a supportive presence. Overall, Yasmin's story follows a stability-focused structure, emphasising ongoing management rather than resolution or recovery.

***Anaya ****

Anaya first noticed symptoms in her early to mid-twenties after coming off the contraceptive pill. These symptoms were initially diagnosed as adenomyosis, and she was advised to return to the pill, as no alternative interventions were offered. She later discontinued the pill again when trying to conceive. Her path to an endometriosis diagnosis was shaped by

a miscarriage, as she felt her symptoms were only taken seriously once they failed to resolve, prompting further investigation. Prior to this, she described feeling dismissed by healthcare professionals, despite having suspected endometriosis for several years. She reported experiencing painful menstrual cramping and expressed ongoing frustration at the lack of effective treatment options.

She described experiencing endometriosis differently on different days, reflecting the fluctuating nature of her symptoms and feelings. She chose to seek private healthcare due to long NHS waitlists and hearing about friends' experiences, highlighting her proactive approach to managing her condition. Recently married, she reflected on how endometriosis has affected her relationship, noting both emotional and practical support from her partner. She also sought support from therapy and friends, acknowledging that external appearances often do not reflect the pain and emotional impact she experiences internally.

Cultural influences shaped her approach to her health. Coming from an Indian background, she did not always share information about her symptoms with family, both because of taboos around periods and a lack of understanding about medical issues. She also noted that cultural beliefs, including respect for non-Western medicine, influenced how she managed her health.

Over time, Anaya described feeling empowered to talk about endometriosis and noticed that her cousins and other female family members now look to her for guidance and support. Her narrative reflects ongoing adaptation, self-advocacy, and the creation of a supportive network within both family and social contexts.

***Aisha****

Aisha's endometriosis journey began before her teenage years, within a family context where periods were not talked about and were shaped by strong cultural taboos. As a result, she initially felt unable to speak openly about her symptoms, although over time she became

less embarrassed discussing menstruation. She described finding it difficult to explain endometriosis to others, as her symptoms were often minimised and reduced to "just painful periods." She repeatedly attended medical appointments and missed significant amounts of school due to pain. During her college years, her symptoms escalated to the point where she attended A&E almost every month. She was eventually referred to the cancer pathway, where scans led to an endometriosis diagnosis. She described feeling consistently invalidated by healthcare professionals and felt she was not given adequate pain relief.

Aisha reported trying multiple forms of contraception as treatment. One hormonal pill had a severe impact on her mental health, making her feel suicidal, and she expressed concern about being prescribed medication in ways that were not always researched. She described frustration at the lack of research and resources available for endometriosis.

Emotionally, Aisha described feeling isolated and dealing with her condition alone for a long time, taking time to open up to others. She reflected that prolonged medication use left her feeling disconnected from her sense of identity. She also spoke about racialised experiences in healthcare, feeling that she was perceived as "hysterical" because she is a Brown woman. While endometriosis affected her ability to form close relationships, she identified her parents as a key source of support. She also described faith as a meaningful escape and coping resource throughout her endometriosis journey.

***Amira***

Amira's endometriosis journey began in her teenage years, marked by heavy and painful periods. She described repeated dismissal by gynaecologists and doctors, which led to a loss of trust in healthcare professionals. She felt that being South Asian contributed to not being taken seriously, and cultural taboos surrounding women's health influenced who she felt able to talk to within her family.

She expressed significant frustration with the limited treatment options available for endometriosis. Multiple forms of contraception were difficult to tolerate and had a negative impact on her mental health, including experiences of suicidal thoughts. She described endometriosis as debilitating and reflected that the normalisation of her symptoms by others affected how she understood and responded to her own pain, often feeling pressure to "shut up and get on with things."

Amira noted a clear contrast between NHS and private healthcare experiences and received her diagnosis through private care. Friends were identified as a key source of emotional support. Over time, she became more open in talking about her endometriosis and described herself as still exploring what it means to live with the condition. Faith was highlighted as an important coping resource throughout her journey.

***Eileen***

Eileen described feeling isolated throughout her endometriosis journey, which was marked by painful periods, irregular bleeding, and painful sex. She expressed fear and uncertainty about her ability to have children in the future, which added to the emotional impact of her symptoms. Cultural stigma surrounding menstrual health made it difficult for her to speak openly about her experiences.

Medication played an important role in managing her symptoms, though she initially found it hard to share the full extent of her difficulties with doctors and attempted to conceal how unwell she was. Over time, building a trusting relationship with her gynaecologist enabled her to open up more fully. She received her diagnosis through private healthcare. Endometriosis had a significant impact on her mental health, and she described feeling low, stressed, and anxious. Her partner was identified as a key source of emotional support. She also spoke about using prayer and meditation as coping strategies. Eileen emphasised the need for greater

awareness and education about endometriosis, reflecting her hope for improved understanding and support for others.

***Mary***

Mary's endometriosis journey began in her teenage years and was marked by severe cramps and heavy bleeding. She described feeling grateful once she received a diagnosis, as it allowed her to feel believed after a long period of uncertainty. Prior to this, repeated dismissal by medical professionals led to a loss of trust in healthcare.

She eventually found a gynaecologist independently who validated her experiences and feelings, which marked an important turning point in her journey. Endometriosis had a significant impact on her mental health, contributing to feelings of depression and placing strain on her relationship with her partner. Over time, she described learning to create more time and space for herself in response to her condition.

Mary identified her family as a key source of support, alongside online support groups, which she found helpful for connection and understanding. She managed her symptoms through a combination of pain medication and exercise. She also reflected that cultural stigma and taboos around women's health contributed to delayed diagnosis, as her family were initially unaware of endometriosis and available supports. Faith was described as an important coping resource, and she reflected that endometriosis has significantly changed her life.

***Laila***

Laila began experiencing symptoms of endometriosis in her teenage years but did not seek medical help until her early twenties. Her symptoms included heavy bleeding, severe cramps, and painful sex, which she described as overwhelming. Endometriosis significantly affected intimacy, and she found it difficult to talk openly with her partner about these challenges. She reflected that cultural teachings framing women's health and menstruation as taboo contributed to this silence.

She described feeling as though she had to convince others of the reality of her pain and fatigue in order to be believed. Religion played a complex role in her experience; prayer and meditation were helpful coping strategies, while religious and cultural narratives that reinforced menstruation as taboo were experienced as unhelpful.

Laila took an active role in seeking support, researching where to access care herself. She described a positive experience with a gynaecologist, feeling listened to and validated. Friends and family were identified as important sources of support, alongside an online community. She also made lifestyle and dietary changes in an effort to manage her symptoms. Endometriosis had a notable impact on her mental health, contributing to feelings of depression, anxiety, low self-esteem, and isolation. Her story reflects ongoing efforts to cope, seek understanding, and manage the emotional and physical effects of endometriosis.

***Margaret***

Margaret described a mix of relief, anxiety, and uncertainty following her endometriosis diagnosis. She first noticed that something was not right in her early twenties, experiencing ongoing pain, heavy bleeding, and fatigue. Her cultural background strongly shaped how she understood and spoke about these difficulties, and she described growing up in a patriarchal society where women's health and feelings were often overlooked, leading to feelings of shame.

She reported being dismissed by some medical professionals, who she felt lacked adequate knowledge about endometriosis. Support came unexpectedly through a neighbour, who recommended a hospital and a gynaecologist and became the first person she spoke to about her experiences. She was diagnosed at a private hospital and described feeling validated by both her neighbour and her gynaecologist. Receiving a diagnosis also allowed her to challenge and "prove wrong" family members who had previously minimised her symptoms.

Endometriosis placed strain on her relationship with her partner and had a significant emotional impact, contributing to anxiety, isolation, and feelings of disconnection from others. Her partner was identified as an important source of support. She managed her symptoms through exercise and yoga and expressed a desire to connect with others with endometriosis, such as through a support group, though she had not yet found one.

Faith and prayer were described as important coping resources. Margaret also expressed concerns about fertility, given the high cultural importance placed on having children. She emphasised the need for more spaces within her community for women to talk openly about their health and emotional experiences, in order to reduce delayed diagnosis for others.

***Aria***

Aria described struggling emotionally with anxiety, depression, and frustration throughout her endometriosis journey. She experienced prolonged and irregular periods alongside pelvic pain, but found it difficult to articulate what was happening to her, which contributed to delays in diagnosis. Endometriosis affected her relationship with her partner and added to her emotional distress. While waiting for a diagnosis through the NHS, she sought private care in order to access medication more quickly. She described receiving significant support from her family, particularly in helping to care for her two children during periods when her symptoms were most severe.

Aria found it helpful to connect with others living with endometriosis during her treatment, gaining advice and emotional support through shared experiences. Faith, particularly prayer, was described as an important coping resource, alongside therapy, which she sought to help manage the emotional impact of endometriosis. She also reflected on cultural influences that encouraged silence around women's health, observing others who remained quiet about their difficulties. In response, she made a deliberate decision to speak openly about her condition and actively seek help, rejecting silence as a coping strategy.

## Narrative Themes

Six interrelated themes were developed through thematic narrative analysis of participants' stories. In keeping with a narrative and PCF orientation, this chapter centres participants' accounts as storied representations of their lived experiences, attending not only to what events occurred but also to how they were narrated, sequenced, and structured, and the narrative features and tools used to convey meaning over time. Participants' voices are prioritised, with extended extracts used to preserve the coherence, emotion, and context of their narratives. Analytical commentary is intentionally limited in this chapter, allowing participants' stories and the narrative features they employ to stand on their own terms. More interpretative and theoretical analysis is taken up in the subsequent discussion chapter.

**Table 8.**

*Summary of Narrative Themes and Sub-Themes*

| Narrative Themes | Sub-themes |
|---|---|
| **"I knew something wasn't right": Early pain, confusion, and the normalisation of suffering** | • Returning to the Beginning: "From My Very First Period"<br>• Medical Normalisation and Dismissal by Doctors<br>• Familial and Cultural Normalisation of Pain<br>• Internalising Normalisation and the Emergence of Self-Doubt<br>• Pain as a Central Narrative Anchor |
| **"I had to push": lack of clinicians' knowledge, self-advocacy and navigating the system** | • Perceived "Lack of Clinicians' Knowledge" and Inadequate Treatment<br>• Becoming One's Own Advocate: "I Had to Push"<br>• Systemic gender and cultural biases<br>• Healthcare professionals as agents of power: villains, gatekeepers, and heroes |
| **Diagnosis as validation, and "now what?": Relief, anger, and searching for information** | • Diagnosis as validation, relief and anger<br>• "Now what?": Living with a diagnosis and uncertain future<br>• The search for information |
| **"It's more than painful periods": Endometriosis as a whole-life condition and an "invisible disease".** | • Emotional impact<br>• Relational impact<br>• Identity impact<br>• Invisibility and Isolation |
| **"It's taboo": Cultural silence, shame, ignorance and learning not to speak** | • Cultural silence around periods and pain<br>• Gendered expectations and fertility pressures.<br>• Working hard to be believed<br>• Unspoken Practices: Navigating Tradition |
| **Resilience, growth and strength** | • Faith and spirituality as support<br>• Resilience and coping strategies |

### *"I knew something wasn't right": Early pain, confusion, and the normalisation of suffering*

Participants' stories consistently began with early experiences of severe and often disabling pain, frequently dating back to menarche or adolescence. Despite the intensity of these experiences, pain was repeatedly framed by both healthcare professionals and those in participants' personal lives as a normal part of womanhood. Over time, these external narratives of normalisation were internalised, shaping how participants understood their bodies and contributing to confusion, self-doubt, and delayed help-seeking.

***Returning to the beginning: My very first period.*** Across participants, narratives frequently began with a return to menarche or early menstruation, suggesting that endometriosis was retrospectively reinterpreted as present from the start. By returning to menarche, stories were structured in a way that positioned it as the moment where pain first entered their bodily experience. This return functioned not only as a chronological starting point but as a narrative device through which participants made sense of long-standing suffering, early normalisation, and delayed recognition. Menarche appeared to symbolise both the onset of bodily disruption and the beginning of gendered expectations around silence, endurance, and "normal" pain, which shaped subsequent help-seeking and self-understanding. Participants positioned themselves as having early embodied knowledge that something was wrong, yet this knowledge was repeatedly invalidated. By telling their stories chronologically, participants also emphasised the length of time they lived with unmanaged symptoms and how early signs were often dismissed or normalised.

> *"I first noticed something wasn't right in my late teens, around the time I started my period. From the very beginning, my periods were extremely painful-not just cramps, but pain that sometimes made me vomit or faint. I couldn't stand or breathe at times, but I was told it was normal and that all girls go through this, so I*

*just tried to cope. As I got older, the symptoms got worse. I started experiencing chronic pelvic pain not just during my period, but even between cycles. I would feel a deep, aching pain in my lower back and legs, and sometimes during sex, which was really confusing and difficult to talk about. I was 17 when I started experiencing these symptoms. I didn't know what was happening and just thought something was wrong with me, but I couldn't explain it." Zara*

Zara uses uncertainty as a structuring device. The account repeatedly returns to not knowing, emphasising a lack of meaning rather than resolution. This account illustrates that rather than progressing toward understanding, the narrative closes in uncertainty, reflecting an unfinished story in which pain is present but unexplained. Similarly, Ulima illustrates how her endometriosis journey began with her first period:

*"I started my period when I was 11 years old, and from the very beginning, every single period was hell. I had days off school every month because of the pain, and this went on for years. I went to the doctors multiple times and told them I had really bad periods, but I was always told it was normal and that the amount of bleeding was normal. I kept saying it wasn't—that I was bleeding a lot—but I was dismissed for years.*

*When I went to university, it became even worse. At one point, I called an ambulance because the pain was so severe. I was first told it was coming, then called back and told it wasn't an emergency and that it was 'just a period,' so they wouldn't attend. Every single period of my life has been awful." Ulima*

Ulima uses repetition and absolutist language. This repetitive structure constructs pain as enduring and inescapable, reinforcing how suffering became normalised over time. Alongside this, normalisation is explicitly voiced through others, locating authority outside the

narrator and shaping how she came to understand her body. This relational normalisation is gradually internalised, leading to coping rather than questioning. References to repeated school absence function narratively as evidence of severity, offering concrete markers of disruption that nonetheless fail to challenge the normalisation of pain. Through this process, Ulima positions herself as young, lacking knowledge, and potentially flawed, reflecting an identity shaped by externally imposed narratives of normality rather than certainty or embodied trust.

Participants' stories not only highlight that endometriosis is present from an early age but also emphasise the ongoing interruption it caused in their lives. Periods were often narrated as the first point of interruption, and, given the cyclical nature of menstruation and the broader impact of the condition, their narratives continued to be repeatedly interrupted over time.

***Medical Normalisation and Dismissal by Doctors.*** Participants frequently described early healthcare encounters in which their symptoms were minimised or framed as typical menstrual discomfort. Within these accounts, doctors were consistently positioned as authoritative gatekeepers of meaning, whose reassurance paradoxically intensified confusion rather than relief. This relational positioning had important implications for how participants narrated their experiences and understood themselves at a young age. Medical professionals were constructed as holding epistemic authority, while participants positioned themselves as young, dependent, and lacking credibility, expected to endure pain rather than question it. As a result, participants' narratives reflect an early erosion of trust in their own embodied knowledge, with medical reassurance functioning to close down exploration rather than alleviate distress. This supports the subtheme of medical normalisation and dismissal as a relational process, in which authority and meaning-making are located outside the narrator, shaping identity formation and contributing to delayed recognition and help-seeking.

*"As a child, my mum took me to the doctor all the time, and when I was at school, I was constantly going to the doctors. I was always told it was nothing and that it was just my period. I was prescribed Feminax, and when I told them it didn't work, they said that was the best they could do. Eventually, I started taking Co-Codamol on my own because I had no choice and was in so much pain. At that point, it was the only thing that helped because it would knock me out, so at least I wasn't feeling the pain." Ulima*

A subtle but important narrative shift is evident in the movement from prescribed treatment to self-directed medication. This shift is not narrated as empowerment or choice, but as necessity. As a narrative feature, this marks a repositioning of agency under constraint, where medical dismissal reshapes the narrator's role from passive recipient of care to reluctant self-manager. Rather than reflecting confidence or autonomy, this form of agency emerges as a response to unmet needs, illustrating how ongoing dismissal forces participants to assume responsibility for managing pain in the absence of adequate medical support. Embedded within these accounts is a palpable sense of abandonment, as participants describe feeling left to navigate debilitating symptoms alone, without validation, guidance, or sustained clinical care. Margaret also highlighted on-going dismissal while reflecting on the broader context in which this dismissal occurred.

*"Although some of the professionals I met were dismissive or distant, I felt that was because they didn't really have much knowledge about endometriosis. Most of them said it was just a woman's problem and that I should deal with it." Margaret*

This account explicitly situates dismissal within a gendered narrative. These expressions draw on wider cultural narratives that de-legitimise women's suffering and locate responsibility for endurance within the individual woman rather than the healthcare system. As

a narrative feature, this reflects participants' use of broader gendered discourses to make sense of their experiences, showing how personal stories are shaped through culturally available narratives about womanhood, pain, and responsibility. This highlights the narrative resources participants draw upon, without yet interpreting their broader social function.

This subtheme highlights the circular/repetitive nature of participants' narratives (Gergen & Gergen, 1983), in which persistent symptoms led to ongoing difficulties and repeated visits to healthcare professionals, with the same concerns being revisited in continual attempts to seek understanding and care.

Across narratives, participants frequently described turning to private healthcare, often due to long NHS waiting times or repeated experiences of dismissal. This shift was commonly framed as a turning point within their stories, marking a move from passivity to greater agency in seeking care. However, it was also seen by many as an act of desperation due to feeling it was the only way to receive care. Participants contrasted these healthcare experiences in ways that highlighted feelings of being overlooked within public services. Angelie articulated this contrast particularly strongly, emphasising a perceived difference in care and attention:

> *"There's a distinct disparity in the interest that doctors have in you when you're paying, and when you're just another number on the NHS register, which is so, so unfair." Angelie*

Angelie illustrates how participants constructed healthcare interactions relationally, positioning private care as more attentive and validating, while the NHS was sometimes experienced as impersonal. The narrative use of contrast and evaluative language serves to reinforce a broader theme of inequality in care and contributes to how participants make sense of their help-seeking journeys.

For some participants, receiving a diagnosis of endometriosis was experienced as a crisis. The severity and persistence of their symptoms raised concerns about serious illnesses, including cancer, prompting an escalation of care through emergency pathways.

> *"And I got my diagnosis on [date]. Once I was on the cancer pathway, it was a lot faster, thankfully. But before that, I had been waiting a long time, and COVID didn't help because everything got delayed or pushed back. Once I had my diagnosis, I went private because I didn't want to wait any longer." Sienna*

Sienna uses temporal sequencing to highlight the contrast between prolonged delay and the sudden acceleration once their symptoms were taken seriously, creating a sense of tension and frustration. The narrative also uses cause-and-effect reasoning, positioning external systems and crises as pivotal in shaping the trajectory of care. There is relational positioning, with Sienna implicitly critiquing healthcare structures and situating herself as an active agent navigating delays through private healthcare. Finally, the narrative conveys emotion through subtle emphasis on exhaustion and impatience, reflecting the embodied and psychological impact of prolonged diagnostic delay.

Anaya similarly narrated her diagnosis as occurring only after her health difficulties were escalated, though in contrast to Sienna, this escalation took place through the maternity pathway.

> *"Previously, I had scans for endometriosis, but they didn't show anything; the professionals couldn't identify or notice anything. However, during the process of having a miscarriage, my body changed and was recovering from that difficult experience. It wasn't the cause of the miscarriage, but it did reveal the endometriosis on the scan. Interestingly, I feel like the professionals only took me seriously at that*

*point because I was pregnant, not because of my endometriosis symptoms. The symptoms alone weren't enough to prompt the scans." Anaya*

Anaya uses contrast and turning points to highlight delays in diagnosis, showing how endometriosis was only recognised during pregnancy. Relational positioning emphasises selective attention from professionals, reinforcing feelings of dismissal. Anaya reflects on causality and implicitly critiques medical authority, showing that legitimacy was granted externally rather than through their own embodied experience.

A clear narrative tension emerges around participants' experiences of healthcare. While the majority described GPs as dismissive or encountered repeated obstacles within the system, a smaller number of stories recounted positive interactions from the outset. This tension highlights the variability of healthcare encounters and shapes participants' stories, positioning professionals alternately as gatekeepers, obstacles, or allies, and influencing how participants narrate their own agency, trust, and understanding of their condition.

*"When I left [birth country] for the UK, I felt like I had access to quality healthcare services...So that was when self-confidence came, and I had to sort of ask for help at the [hospital name]… My experience there was a good one because you have people who listen to your symptoms, people who are willing to help. I was able to share my story, and you have people who understand what endometriosis is. So my experience was a positive one. They are compassionate, they have empathy. It was a good experience because I was treated with kindness, respect, and compassion by staff." Laila*

Laila foregrounds being "listened to" and "able to share my story," framing care as a process in which her experiential knowledge is recognised. Repetition of evaluative language works as a contrast to earlier accounts of dismissal, highlighting the significance of empathy

as a narrative turning point. Although Laila speaks of a positive experience in the UK, her story does not start in the UK. She uses migration as a narrative turning point, with movement to the UK framed as a shift in access, possibility, and self-positioning.

***Familial and Cultural Normalisation of Pain.*** Alongside medical dismissal, participants described families and communities reinforcing narratives of endurance, silence, and normal womanhood. Pain was often positioned as something to be tolerated rather than questioned.

Laila recalls a conversation with her aunt in which she attempted to talk about her pain:

> *"People told me that in our culture, periods are not talked about openly because I remember telling my aunt about my pain, and she said it's part of being a woman, you have to be strong. And this idea that stopping is silence is noble. And I don't feel I had the language or the permission to speak about what I was experiencing." Laila*

Laila brings in an external voice to demonstrate cultural and familial normalisation of experience. Through relational positioning, Laila situates herself in relation to her aunt, whose words communicate cultural expectations about endurance and "strength." The use of direct quotation preserves the voice of authority, while cultural reflexivity highlights how these norms shape meaning and behaviour. Metanarrative reflection is evident as Laila notes her lack of language or "permission" to speak about their pain, demonstrating how familial and cultural expectations are internalised and influence self-understanding.

***Internalising Normalisation and the Emergence of Self-Doubt.*** As dismissals accumulated across contexts, participants began to question their own perceptions. Several spoke of doubting whether their pain was real or whether they were "overreacting." This subtheme captures how external messages of normalisation from doctors, family, and wider

cultural narratives became internalised, shaping participants' understanding of their bodies and experiences. Over time, repeated minimisation and authoritative reassurance led to self-doubt, positioning participants as uncertain, dependent, or potentially flawed, and influencing how they interpreted symptoms and narrated their early illness experiences.

> *"At first before I even got the diagnosis, I remember feeling confused and frustrated. I knew something was wrong with my body, but I kept being told it's just your pain or you're exaggerating. That makes me feel like I couldn't trust my own experiences. At a point I started questioning myself, you know? Is this pretty normal? Am I overreacting? You know, that can really weigh you down mentally." Zara*

Zara's use of internal dialogue and reported speech are key narrative tools to convey epistemic uncertainty. By reproducing what she was told alongside self-directed questions, Zara shows how external dismissal becomes internalised, transforming medical minimisation into self-doubt. The repeated questioning marks a fracturing of narrative authority, where confidence in bodily knowledge is eroded and replaced by uncertainty. Emotion words such as "confused," "frustrated," and "weigh you down mentally" function to link epistemic disruption with psychological burden, illustrating how disbelief reshapes both the story and the self as uncertain, unreliable, and mentally strained. Amira illustrates how this continued even after a formal diagnosis was received:

> *"I think disbelief was the main thing I felt because I thought, how could it have been missed so many times? Having been dismissed so often, I'd convinced myself that I was overreacting. So when he confirmed it, I kept asking, 'Are you sure?' and he said, 'Yes, I'm sure.' It took me a while to accept that this was real, but I did feel relief and, mainly, validation—that my experiences are real and that I'm not being too much or exaggerating. This is a real condition." Amira*

These narratives positioned participants as reliable knowers of their own bodies, yet lacking the legitimacy or language to have this knowledge recognised. The delay in diagnosis was experienced not only as a medical issue but as a prolonged period of epistemic injustice, where bodily pain was known but not believed.

***Pain as a Central Narrative Anchor.*** Pain functioned as the organising centre of participants' stories. Narratives repeatedly returned to pain, and it ran through stories at different points as something that demanded explanation, legitimacy, and recognition. Pain was not only physical but moral and relational, used to justify help-seeking, to explain absence, and to contest dismissal.

> *"It was just the pain. It was just the lower abdomen pain. Like, just feeling like my stomach is twisting and like knives are being stabbed into my stomach like, you know, the pain was so bad. When I gave birth to my children, I took no medication. I refused to take the epidural. I refused all medication because I kid you not, giving birth was less painful than having a period…And giving birth is painful. And when the contractions go super high, like when they were really, really high, like when you're, like, reaching 98, you know, that is the type of pain that I was feeling on my period."*
>
> *Ulima*

The use of the simile, such as "like knives are being stabbed into my stomach," intensifies the narrative by providing a concrete, sensory image of the pain. This figurative language helps the reader viscerally understand the severity of the experience and reinforces pain as a narrative anchor, around which the story's meaning, comparisons (to childbirth), and emotional weight are structured. It also conveys the inescapable and penetrating nature of the pain, making it central to the participant's lived experience. Aisha also described how the pain

was inescapable, permeating multiple aspects of her daily life as well as that of those around her:

> *"And I think when it came to being in pain, no one could do anything for me. My parents, bless them, would stay up with me at night, refill my hot water bottle, take me to A&E, but there was nothing anyone could actually do. So I spent the majority of that time just by myself." Aisha*

The structural positioning of pain at the centre of the story frames the narrative around the participant's suffering, making it a narrative anchor that organises events and relationships. Absolutist language heightens the sense of inescapability and isolation, while relational positioning shows the participant's awareness of supportive others who are nevertheless unable to alleviate the pain. Together, these features make the embodied experience of pain both the driving force of the story and a lens through which the narrator interprets social and familial interactions. Eileen further adds to the narrative of pain by discussing the emotional and embodied impact:

> *"After three months of severe pain, I couldn't hold it anymore. There was a time I was crying, and I had to share with a family member." Eileen*

Eileen centres pain as a pivotal embodied experience. The use of absolute language is used as evidence of the intensity and inevitability of the experience, making the pain feel inescapable and central to the narrative. It emphasises endurance and suffering, reinforcing pain as a narrative anchor around which the story is organised.

***"I had to push": lack of clinicians' knowledge, self-advocacy and navigating the system***

This theme captures participants' accounts of prolonged, emotionally taxing interactions with healthcare services, in which they repeatedly sought recognition of their pain and symptoms. Across narratives, healthcare settings were described as sites of both

frustration and eventual validation, requiring participants to persist, return, and increasingly advocate for themselves.

***Perceived Lack of Clinicians' Knowledge and Inadequate Treatment.*** Across accounts, participants questioned the level of knowledge held by healthcare professionals, particularly in primary care. Many described being offered painkillers or hormonal contraception without meaningful investigation, framing these responses as insufficient or dismissive. Birth control was often narrated as a "temporary fix" that masked symptoms rather than addressing underlying causes. Here, participants positioned themselves as recognising gaps in medical understanding, contributing to feelings of frustration and mistrust toward healthcare systems.

> *"I wish I had never had the operation. I feel like I went under the knife for nothing, because I still had all the pain and symptoms…I don't believe the NHS can do much for endometriosis. I feel that many practitioners aren't fully informed—they don't know when or how to diagnose it. We go through years of pain and are told it's just period pain, when in fact it's not normal. It's not like the small amount of bleeding they show in school; I used to pass 10 to 15 blood clots in one sitting" Ulima*

Ulima describes retrospective regret over her treatment, which prompts reflection on the healthcare system. A key narrative feature is the use of embodied evidence as narrative warrant. Ulima provides vivid, concrete descriptions of bodily experiences to substantiate the severity of symptoms, to function as narrative evidence, directly challenging normalisation and rebutting dismissive frames like "just period pain." By foregrounding the body itself, Ulima legitimises her experience and asserts authority over the story of their illness.

Margaret further illustrates how healthcare professionals' lack of knowledge shaped the way they framed her endometriosis:

> *"Some of the professionals I met were dismissive or distant. I felt this was because they didn't have much knowledge about endometriosis. Many just said it was 'a woman's problem' and that I should deal with it. I was lucky to find one professional who recommended [hospital name], and that's where I was diagnosed." Margaret*

Yasmin extends this perspective by situating GPs within the broader healthcare system, highlighting how their actions and attitudes reflect systemic patterns rather than isolated encounters:

> *"I'd go to the GP and they'd say… 'It'll settle.' I'd go back a year later… 'Oh, you're really young. It'll get OK.' Then they'd say things like… 'maybe this is just your normal.' I was thinking, if this is normal… I don't want to see what not normal's like… I'd been referred to gynes a couple of times… They do scans…they'd tell me things like, 'your BMI is a little bit high, maybe just lose some weight and that'll help.' It just felt… almost like blaming… I had to be the person to… lose weight to feel OK… Whenever I'd get referred back to gynes, I just had a really bad experience… being told that there's nothing wrong." Yasmin*

Across accounts, participants narrated a reversal of epistemic authority in relation to healthcare professionals. Early encounters positioned doctors as definitive gatekeepers of what counted as "normal," but later narratives constructed professionals as lacking the knowledge to recognise or diagnose endometriosis. Participants explicitly questioned clinical expertise and positioned themselves as able to identify abnormality through sustained embodied experience,

using the persistence, severity, and incongruity of symptoms as narrative evidence. Collectively, these accounts re-centre experiential knowledge as a legitimate source of authority, challenging earlier constructions in which epistemic power resided solely with clinicians.

***Becoming One's Own Advocate: "I Had to Push".*** Over time, participants described a shift in narrative position, moving from passive recipients of care to active self-advocates. This included returning to GPs multiple times, tracking symptoms, researching endometriosis independently, requesting referrals, and sometimes challenging professional authority. Several participants described this process as exhausting but necessary to secure diagnosis and treatment. This subtheme marked a turning point in many stories, reflecting increased agency and resilience, while also highlighting the emotional burden of having to "fight" for care.

> *"I think being aware of how limited women's healthcare resources are makes it even more important to think about how endometriosis is understood and treated. For me, culture definitely intersects with this. I've learned that the way to navigate the healthcare system in this country is to stick to the facts, focus on symptoms and medication, and advocate for yourself in a very specific way. That might be one of the reasons I eventually got a diagnosis, although I don't know for sure.*
>
> *I often wonder whether my experience would have been different if I wasn't a South Asian woman, or whether I might have received a diagnosis sooner. It makes me think that cultural understanding within services is really needed, not just across the NHS generally, but especially for endometriosis. Conversations about symptoms and emotional impact are not always happening at home, and if services assume that people have support systems in place, that isn't always the case. I think that gap is really important." Aaliyah*

This account demonstrates metanarrative awareness, with Aaliyah explicitly reflecting on how illness stories must be told to be recognised. Aaliyah signals an understanding that being heard by medics requires a particular mode of telling that prioritises symptoms, medication, and clinical language. Rather than rejecting medical authority, Aaliyah shows a negotiation of epistemic authority, where knowledge is framed as procedural and strategic rather than purely biomedical. The story remains structurally open, rather than resolved or closed. Cultural reflexivity is also foregrounded, as the participant situates their experience within wider reflections on gender, race, and healthcare systems, questioning whether being a South Asian woman shaped access to diagnosis and support and drawing attention to how cultural assumptions and structural gaps in care are woven into personal illness stories.

***Systemic Gender and Cultural Biases.*** Participants frequently reflected on the ways their experiences of endometriosis were shaped by intersecting gendered and cultural assumptions within healthcare. Some perceived that male patients with comparable symptoms might receive faster referrals, more validation, or greater access to interventions, highlighting structural inequities in medical treatment. In addition, participants described experiences in which their South Asian identity influenced how seriously clinicians took their symptoms, with assumptions about cultural norms, pain tolerance, or family dynamics sometimes contributing to delayed diagnosis or insufficient care. These intersecting biases compounded participants' frustration and feelings of dismissal, reinforcing the challenges of advocating for care within a system that often underestimates both women's pain and the impact of cultural identity.

> *"I wouldn't say I'm happy with the treatment choices I've been offered. The old comment, 'It only matters if you want to get pregnant,' isn't helpful. But at the same time, I'm not surprised. Funding for women's health isn't nearly enough. The more you learn, the more it becomes clear that if men had this condition, there would*

*probably be a cure. Men's pain is often heard, listened to, and validated. They get referrals without having to fight for it. I don't doubt that if men experienced this, treatment would be adequate. You only need to look at men's health—how much funding, attention, and treatment options exist compared with women's health—to see the disparity." Aaliyah*

Aaliyah's account draws on comparative narrative framing, contrasting men's and women's healthcare to make inequity visible. She mobilises wider cultural narratives about gender, funding, and the legitimacy of pain to contextualise personal dissatisfaction with treatment. Through declarative and generalising language, the narrative shifts from individual experience to structural critique, positioning gendered injustice as an explanatory framework for ongoing treatment limitations. Aisha adds to this by discussing the implications of not only being a woman, but being a woman from a racialised background:

*"I think being a brown woman immediately puts you on the back foot. I read about something called Bibi syndrome… I was probably on the receiving end of a lot of that. People see a brown woman and think she's just hysterical, that she doesn't really know. I feel like a lot of healthcare professionals talk to me like I don't understand what's going on, like I can't string a sentence together in English, so they can dismiss me and fob me off." Aisha*

This narrative employs explicit identity positioning, with race and gender foregrounded as shaping how the participant is perceived and treated. The account draws on a racialised cultural narrative to explain dismissal, while also demonstrating metanarrative awareness of how credibility is socially assigned. Through evaluative language, the participant positions herself as epistemically undermined, highlighting how intersecting identities function as narrative resources for making sense of unequal healthcare encounters.

***Healthcare Professionals as Agents of Power: Villains, Gatekeepers, and Heroes.*** Across participants' narratives, healthcare professionals occupied shifting and sometimes contradictory roles. Early encounters were frequently narrated as antagonistic, with professionals positioned as dismissive figures who normalised severe symptoms, questioned credibility, or offered inadequate treatments. These interactions often contributed to delayed diagnosis and self-doubt, with some participants describing internalised dismissal and self-gaslighting.

> *"You know, there are a few negative experiences. I would say the negative experiences I've had were the times I was dismissed by GPs. I remember one GP telling me that some women just have low pain tolerance, and that I should take stronger painkillers and rest more. That was really hurtful, not just physically but emotionally. I left feeling brushed off and embarrassed, like I had made a big deal out of nothing." Zara*

Here, the GP is narratively constructed as a "villain" through relational positioning, where the participant is framed as vulnerable and dismissed while the doctor holds epistemic authority. Evaluative language such as "hurtful," "brushed off," and "embarrassed" conveys the emotional impact and moral weight of the encounter. Zara uses a specific anecdote as a narrative warrant, detailing the GP's words and actions to justify this positioning. Additionally, cumulative framing situates this experience within a pattern of repeated dismissal, reinforcing the systemic nature of medical minimisation.

> *"I'd been to A&E before when they had only seen cysts on my early scans—maybe the first or second scan before my MRI and diagnosis. A male doctor told me I shouldn't be there because I had a small cyst on my ovary. I remember my mum*

*opened the curtain and asked for another doctor, and I sat and cried. I said, 'Let me stick it in you and see how you feel.' That really stuck with me." Aisha*

This story reinforces and extends the "GP as villain" narrative by highlighting relational positioning and gendered power dynamics. The male doctor is framed as dismissive and unsympathetic, while the participant is vulnerable, emotional, and delegitimised. The use of direct speech functions as a vivid narrative anchor, emphasising the injustice and moral evaluation of the encounter. Specific anecdotal detail, the setting in A&E, the mother intervening, and the act of crying provide narrative warrant, grounding the broader critique of medical dismissal in concrete events. Together with the earlier example, it shows a pattern of repeated minimisation across contexts, illustrating how medical authority is narratively constructed as both gatekeeping and emotionally harmful.

However, following diagnosis or contact with specialist services, healthcare professionals were often re-positioned as allies and/or sources of validation. Participants described feeling listened to, believed, and treated with compassion, marking a significant turning point in their illness narratives. It was noted how one interaction could make them feel validated and heard in a way they previously had not felt. In this way, healthcare professionals functioned both as barriers and as facilitators within participants' journeys, shaping not only access to care but also participants' sense of legitimacy, agency, and voice. This dual positioning highlights the relational nature of care and the profound impact of being believed. Nonetheless, it is noted that this positioning could fluctuate and was not stable across stories.

*"I was really happy when I saw my gynaecologist, because I remember my gynaecologist asking me about my period cycle—how long, how heavy, how painful. My gynaecologist also asked about pain during sex, bowel movements, and how the*

*symptoms affected my daily life. At that point, I felt I had someone who could validate my symptoms, someone who was ready to listen to me." Zara*

*"That was because she met me. We had a really honest and open conversation. I felt like I was talking to someone who understood me and was actually trying to understand where I was coming from. Someone who didn't see me as an idiot or think I was naïve and didn't understand what was going on, and who actually listened to what I'd been through. She had gone through my notes and seen that this was a consistent issue, that the pain wasn't under control, and I was having to go to A&E for that. She asked, why would we send you to A&E when we can manage that in GP? That felt like a really big breakthrough for me. It was like, thank God, I don't have to sit in a plastic chair for nine hours, I don't have to worry about not sleeping, because it's there—I can get the pain relief." Aisha*

Here, relational positioning is key: the gynaecologists are framed as attentive, validating, and empathetic, directly contrasting prior experiences of dismissal. Detailed, concrete description of their actions: asking about cycles, bowel movements, sex, reviewing notes serves as a narrative warrant, showing that their care is evidence-based and thorough. The use of first-person reflection conveys the emotional significance of being heard, highlighting the therapeutic and supportive role of these clinicians. Contrast and sequence are also employed: the narrative moves from past neglect and frustration to relief and trust, emphasising a shift in epistemic authority. Participants can now rely on an external figure who acknowledges their embodied knowledge, rather than feeling isolated or disbelieved.

***Diagnosis as validation and "now what?": Relief, anger, and the search for information***

Receiving a diagnosis was described as a powerful narrative turning point, often characterised by relief and validation. However, diagnosis also prompted retrospective anger

about delays in care and reflection on how life might have been different if participants had been listened to earlier. Many described mourning missed opportunities, deteriorated health, and altered futures. Alongside this, diagnosis frequently exposed a lack of clear guidance or information, requiring participants to actively search for understanding beyond clinical settings. This dual positioning of diagnosis as both resolution and rupture was consistent across narratives.

Diagnosis was therefore not narrated as an ending, but as a reframing of the self and the past. Participants looked backwards to reinterpret earlier experiences and forwards into an uncertain future marked by chronicity, fertility concerns, and ongoing self-management rather than cure, often navigating this future through independently sought knowledge and support.

***Diagnosis as validation, relief and anger.*** Participants describe relief that their symptoms are recognised and legitimised, confirming that their pain was real; however, this was a complex and nuanced emotional experience. Narratively, this shifts their self-positioning from doubting themselves to credible experiencers of their condition.

> *"I feel relieved to finally have a name for what I've been going through for years. I was in pain, and it felt like no one believed me, not even doctors sometimes. Getting a diagnosis made me feel validated, like I wasn't imagining things and my pain had a real cause…I also feel angry and frustrated because it took me so long to get here. I kept thinking that if someone had listened earlier, maybe things wouldn't have gotten this bad. There's also sadness, especially when I think about how it affects things like fertility, energy levels, and just being able to live life normally."*
>
> *Zara*

This account uses emotional layering to hold relief, validation, anger, and sadness simultaneously, reflecting a non-linear meaning-making process. The diagnosis functions as a narrative resolution, providing retrospective coherence by legitimising past suffering. At the same time, the narrative introduces counterfactual reflection, which keeps the story open and unresolved, linking validation to loss, missed opportunities, and ongoing uncertainty around fertility and quality of life. Aaliyah also narrates a reflection on the diagnosis process:

> *"I think from the point at which I got symptoms, it's been 11 years to get the diagnosis. Which is strange, because now I say it and I think, yeah, that's normal—for endometriosis that's normal when it shouldn't be." Aaliyah*

By narrating her experience, Aaliyah engages in real-time reflection, demonstrating how storytelling can generate insight and reshape personal narratives. The repetition of "normal" serves as a narrative anchor, contrasting her lived experience with external definitions of acceptability, while also underscoring the ongoing challenges and emotional weight of the endometriosis journey, which remain immediate and deeply felt for participants.

***"Now what?": Living with a Diagnosis and Uncertain Future.*** This theme captures the period that follows diagnosis, where certainty does not bring closure but instead opens a new phase of uncertainty. Participants described navigating life with a named condition that offered explanation but no clear resolution, prompting questions about long-term management, fertility, identity, and the future. Narratively, this phase is marked by forward-looking reflection, ongoing sense-making, and the realisation that diagnosis is not an endpoint, but the beginning of living with a chronic condition.

> *"I have a diagnosis, but no one explained what comes next. Navigating this has been difficult because there's no clear pathway. They don't explain, 'This is the*

*next step; this is what we need to do.' Instead, they ask if you have any questions, and I think, 'What questions can I ask? I don't know.' It's really frustrating." Sienna*

This narrative features structural uncertainty, with the absence of a clear care pathway shaping the story's progression. Despite the diagnosis, epistemic authority remains external, and the participant is positioned as lacking the knowledge required to participate meaningfully. The quote highlights a gap between diagnosis and understanding, where institutional silence sustains confusion and frustration rather than closure. Aisha further illustrates the frustration felt by participants following diagnosis:

*"You're basically given a life sentence with this condition. You're told that you're living with it for life, and there's not much that can be done about it. That's literally what it feels like. That then makes it mentally very difficult to move past, because you have to learn to live your life around it rather than it being something you can just get past." Anaya.*

This account employs metaphors to convey the permanence and inescapability of the condition. The narrative frames endometriosis as a biographical disruption, requiring a fundamental reorganisation of life rather than recovery or resolution.

***The Search for Information.*** This subtheme captures participants' accounts of having to independently seek out information about endometriosis in response to gaps in clinical knowledge and limited guidance from healthcare professionals. Many described turning to informal sources such as social media and online communities to make sense of their symptoms and diagnosis. However, these spaces were often experienced as exclusionary, with information and representations largely centred on white users, leaving participants struggling to find stories, advice, or visual representations that reflected their own identities and

experiences. This further compounded feelings of invisibility and highlighted how knowledge gaps are shaped not only by illness but also by race and representation.

Anaya narrates her experience of endometriosis on social media:

> *"Even on Instagram, when people share their own experiences around endometriosis, or they share what life is like, you don't really see anyone from our sort of our background…But I suppose through my own research and looking up things, I've not seen anyone who is the advocate or who is raising awareness for endometriosis? Oh there is that newsreader more recently-can't remember her name. She's South Asian and she's got adenomyosis and she's talked about that. And I was like, I think that's the first time I've seen somebody talk about it." Anaya*

This quote uses contrast and absence as key narrative tools, with the repeated emphasis on "not seeing" people from Anaya's background highlighting representational invisibility within online spaces. The narrative uses search and discovery sequencing, moving from ongoing absence to a rare moment of recognition, which underscores how exceptional representation feels rather than expected. Identity positioning is central, as the participant situates themselves within a racialised community and frames visibility as meaningful validation. The hesitant recall of the newsreader further reflects the scarcity of relatable advocates, reinforcing how limited representation shapes participants' meaning-making and sense of belonging. Zara also highlights how online spaces often lack the nuanced understanding required to support participants from diverse backgrounds:

> *"Where support does exist, I found that it's not always culturally accessible or relevant, especially for South Asian women like me. A lot of the support groups online, resources and even awareness campaigns tend to be very general, and they don't always reflect the cultural pressures and family dynamics or religious sensitivity*

*that shape how we experience illness. You know, for example, issues like talking about periods, sexual health, or even advocating for yourself in medical settings can be a lot more complicated in our community because of gender rules, or respect for elders." Zara*

This quote uses evaluative commentary and contrast to highlight gaps in culturally relevant support. Zara employs identity positioning to situate her experience within a specific social and cultural context, while listing and accumulation functions as a narrative tool to convey the layered complexity of illness experience. By framing support as "general" and culturally misaligned, the narrative foregrounds how broader social norms shape access to care and advocacy, positioning cultural context as central rather than peripheral to understanding endometriosis.

A narrative tension emerges in participants' accounts regarding the usefulness of online information and support groups. While some described an absence of spaces that reflected their identities or experiences, others actively engaged with online communities and found them to be valuable sources of support, validation, and information. This divergence highlights how digital resources can function both as sites of connection and as spaces of exclusion, shaping participants' coping strategies in different ways.

*"So you know I found online support groups, you know, and these groups are really helpful because these are spaces where other women with endometriosis share their stories, the struggles, and you know, tips." Zara*

Collective narration is used to position online support groups as shared spaces of understanding. Positive evaluation frames peer knowledge as a meaningful alternative to formal medical guidance. Through this, experiential knowledge is narratively legitimised, and authority is redistributed from professionals to a collective of lived experience.

*"I know we don't want to name names, but for example, [name]. That's a Facebook group. There's nothing wrong with it. I just find that the mediator is very harsh. And she's not very friendly at all." Sienna*

By focusing on the mediator's role, the narrative highlights how gatekeeping within peer spaces can shape experiences of support, illustrating that not all community-based resources are narratively constructed as safe or affirming.

***"It's more than painful periods": Endometriosis as a whole-life condition and an "invisible disease".***

All participants described endometriosis as extending far beyond "painful periods," framing it as a whole-life condition that affected work, relationships, mental health, identity, and daily functioning. Pain and its management were not experienced in isolation but intersected with cultural expectations, gendered norms, and social roles, shaping both how participants understood themselves and how they were perceived by others. This theme captures the broader impacts of living with endometriosis, encompassing mental health, relational experiences, and self-perception.

***Emotional impact.*** Participants described feelings of frustration, sadness, anger, confusion, anxiety, and guilt in response to their chronic pain and delayed diagnosis. Emotional distress was often compounded by external dismissal and the invisibility of symptoms. Participants narrated the toll on mental health, including self-doubt and the effort required to cope with both physical and emotional suffering. Emotional impact often serves as the lens through which participants interpret other experiences, linking the physical reality of pain with cognitive and affective responses.

*"There are times when I felt really low, especially when the pain wouldn't stop, and when it would stop me from doing normal things like work, seeing friends, or, you*

*know, even just getting through the thing. Yeah, Endometriosis has, you know, really affected my body. It has affected my mind, my self-esteem and my emotions in very different ways." Zara*

Zara integrates physical and emotional suffering, with pain and psychological distress narrated as inseparable. This reflects a thematic narrative structuring in which endometriosis is constructed as a whole-life condition rather than a discrete menstrual issue. By collapsing bodily and emotional domains into a single experiential account, Zara resists reductive framings of the condition and foregrounds its pervasive impact across everyday life. She goes on to speak of the emotional impact and coping:

*"I just feel like I have to cope. But coping with the emotional impact of endometriosis has been a journey, and I've had to find a mix of ways to look after myself mentally because the emotional toll sometimes feels, as you know, heavy as the physical pain. So you know, I found online support groups, you know, and these groups are really helpful because these are spaces where, you know, other women with endometriosis share their stories, the struggles and you know, tips. So it helps to know that I'm not alone." Zara*

Listing multiple affected domains builds a sense of breadth and cumulative weight. The additive structure conveys the pervasive reach of endometriosis across everyday life, helping the reader grasp its impact as layered and ongoing rather than isolated or episodic.

***Relational impact.*** Participants highlighted the effect of endometriosis on relationships with partners, family, and friends. Pain during sexual activity, fatigue, and unpredictability of symptoms affected intimacy, social life, and perceived reliability. Some participants described feelings of isolation, misunderstandings, and the need to educate others about their condition.

This subtheme positions relational difficulties as both consequence and driver of narrative tension, showing how chronic illness reverberates through social networks.

> *"I'm talking about how endometriosis has taken a toll on my intimate relationship. So I was saying that during sex, it has really made things difficult. Most times, emotionally, because I often feel embarrassed, you know, and I always worry that I would be seen as a problem or less of a woman, and also coming from a culture where things like sex or pain are not openly discussed. It has really made it even harder to talk about it with my partner." Zara*

Zara's account illustrates the relational impact of endometriosis through a narrative focus on disrupted intimacy and social connection. Structurally, the use of ongoing temporal language conveys endurance rather than resolution. Zara positions herself as emotionally vulnerable and self-aware, while the inclusion of cultural context situates the experience within broader social norms. Together, these narrative features of temporal sequencing, self-positioning, and cultural framing show how distress is shaped both by the condition itself and by interpersonal and cultural constraints. Aria further illustrates the relational impact of endometriosis:

> *"I've been trying my best to cope, but I found it very difficult to disclose this to some people around me at the beginning. This led to delays in diagnosis and treatment. I've faced many challenges because of this, including pain during sex, which has recently caused me emotional distress." Aria*

This narrative foregrounds relational positioning, with difficulty disclosing illness shaping both social relationships and access to care. Aria positions herself as managing distress privately, while others are implicitly positioned as unavailable or unsafe recipients of

disclosure. By linking concealment to delayed diagnosis and relational difficulties, particularly around intimacy, the account highlights how endometriosis is negotiated within interpersonal contexts, not experienced in isolation.

Most participants spoke of endometriosis not only affecting relationships with partners and family members but also affecting friendships and their ability to engage in work and social events.

> *"I feel like it makes you a bit more guarded because I feel like it makes you look for real friendships. People that really understand…some people can just like easily just fall off and be like ohh you're just complaining again, oh you're making a big deal of it, oh you're having this? Especially if you're having to cancel plans a lot." Sienna*

This story uses causal and reflective narration to link social experiences with emotional responses, showing how repeated misunderstanding shapes the participant's behaviour. Sienna brings in external voices to demonstrate social invalidation and highlight the barriers these reactions create in forming genuine friendships. Identity positioning is also evident, as Sienna situates herself as someone seeking understanding while negotiating stigma, disbelief, and relational challenges within their social world.

A common narrative amongst participants was feeling that people around them, especially partners and family, wanted to help but did not know how. Yasmin illustrates this by talking about her partner:

> *"He's definitely very supportive. He's got fibromyalgia, so we're a concoction of medical health conditions, and he understands what pain is like. Obviously, he wouldn't understand my pain, just like I wouldn't understand his, but he understands*

*how a painful health condition can take a toll, put you out of action, and make you feel tired. He's very supportive and always says, 'Don't worry, we'll get through it together' and 'You're not by yourself,' which is nice to have.*

*There are times when he knows what I have but doesn't know how to help. He feels helpless. In the moment, if I'm rolling around in a ball on the floor, he'll ask, 'Do you want a hot water bottle? No. Just water? No. Tea? No. What do you want?' And I just say, 'Leave me alone.' That's just him trying to help, but he doesn't know how.*

*I think if people understood the logistics of what's actually happening, and they didn't just see someone rolling around in pain, they would understand what's going on. Even if they wouldn't immediately know what to do, they would know what to say and how to help." Yasmin*

Yasmin uses relational positioning to position herself as experiencing extreme pain, while positioning her partner as caring but uncertain. This helps to communicate how chronic illness changes social roles and expectations in relationships. She also uses contrast as a narrative device; this helps to highlight mutual recognition of suffering without complete empathy, creating a sense of both closeness and limitation in understanding, showing relational tension.

***Impact on work, functioning and identity.*** Participants' narratives highlighted the profound impact of endometriosis on their working lives, daily functioning, and sense of self. Ongoing pain, fatigue, and cognitive difficulties disrupted career trajectories and everyday roles, often in ways that were not visible to others. These experiences were frequently described as frustrating and disorienting, particularly where participants felt misunderstood, judged, or misrecognised within professional and social settings.

> *"I was working in an office in [location] for an oil and gas company, and I was really struggling. I just couldn't cope. Before that, I had been working in the accounts department, and the CEO actually approached me and encouraged me to move into sales after seeing me at a charity fundraiser. I took the role, and I absolutely loved it, but I was constantly exhausted. I was travelling to [city] all the time, and no one really knew how unwell I was. People just thought I was always tired or complaining…People thought I was just moaning or didn't want to work, but that wasn't true at all. I had ambition and big dreams. I believed I would be successful. Now, when people see me and realise I'm at home homeschooling my daughter, they're shocked. They tell me they thought I would be a CEO by now. I really believe that endometriosis has had a massive impact on my life." Ulima*

This quote exemplifies narrative meaning-making, showing how Ulima structures her experience as a story of loss and misrecognition. She conveys not just that endometriosis affected her work, but how it reshaped her identity in contexts where others misunderstood or misjudged her, highlighting tension, movement, and personal meaning within the narrative. Ulima also engages in retrospective meaning-making, where the diagnosis allows the story to be re-read with coherence. Earlier confusion becomes meaningful in hindsight. Ulima also illustrates how the impact of endometriosis on her identity led to looking for alternative explanations:

> *"On the outside, everything seemed positive. I was motivated, ambitious, and had always been that way. I was the first woman in my family to go to university. I completed my degree and my master's and had ambitions to do a PhD. I had always been driven, and people around me knew that. I wanted to succeed, and I knew I was capable. But something was always holding me back. At one point, I even started*

*thinking maybe something had been done to me, like black magic or nazar, because I couldn't understand why I felt this way all the time." Ulima*

This quote illustrates cultural meaning-making, as Ulima draws on cultural explanations to make sense of suffering in the absence of medical answers. Here, cultural narratives function as tools for interpreting and framing unexplained suffering. Aaliyah illustrates the impact of endometriosis on identity by reflecting on how the condition affected the external appearance of her body:

*"And for me, Endo belly is a real issue. I remember before I got the diagnosis, my sister would always say my stomach looked out of proportion to the rest of my body, and I was like, ah, yeah. Now I'm like, yeah, it really does. That was the point where I thought, yeah, this isn't what my stomach's supposed to look like…it affects what you can wear and very mundane things other people don't have to think about. At the moment, I'm wearing really stretchy pyjama bottoms because if I don't, I'm going to be in pain. The only comparison people talk about…is pregnancy…. Endo belly isn't a pregnancy belly, but it can come out to the point where someone could easily mistake it for being pregnant.. Not knowing what your body looks like can be concerning and can affect self-esteem and how you view yourself." Aaliyah*

Aaliyah uses vivid embodied description as a narrative feature, highlighting how physical changes are experienced and interpreted over time. Structurally, the narrative moves from external observation (sister's comment) to internal recognition, linking bodily experience to everyday life, self-perception, and identity, showing how mundane details become meaningful within the story of living with endometriosis.

***Invisibility and Isolation.*** Participants emphasised the invisibility of endometriosis, noting that because symptoms are often hidden, their experiences were frequently dismissed or misunderstood, intensifying emotional distress and social challenges. This invisibility required constant explanation and emotional labour, often resulting in withdrawal from social relationships.

> *"I just wish more people, especially in healthcare, and within our own communities, understood that endometriosis is not just bad periods. It's a chronic and often invisible illness that can be incredibly isolating. I've learned to advocate for myself more, to take support and, you know, try to break the silence around Women's Health, especially for women who look like me." Zara*

This quote draws on several narrative features to convey meaning. Zara uses contrast ("not just bad periods") to challenge dominant normalising narratives, while categorising language ("chronic," "invisible illness") reframes endometriosis as a serious, long-term condition. Relational positioning extends responsibility to healthcare systems and communities, highlighting isolation as a socially produced experience. The narrative also includes identity positioning and agentic self-repositioning, as it frames self-advocacy and silence-breaking as responses to invisibility and misunderstanding. Anaya further illustrates the invisibility of endometriosis:

> *"It must be so hard to actually truly understand how endometriosis impacts you in the body because there are those moments where you can look and feel great, or you might look great, but inside there's so much pain going on, but it's not how someone visualises the pain…you haven't got a wound that you're walking around with, or a cast that's really seen. And I think it's really hard for some people to see the stark contrast." Anaya*

Here, visual imagery and comparison are key narrative tools to convey the invisibility of endometriosis. By contrasting internal pain with visible markers of injury, such as a "wound" or a "cast," it highlights the disconnect between appearance and embodied suffering. This comparative imagery functions to make invisible pain legible to the listener, while also underscoring the narrative tension between looking "great" and experiencing significant internal distress. In doing so, it positions invisibility itself as a central feature of the endometriosis illness experience and a barrier to being understood or believed.

### *"It's taboo": Cultural silence, shame, ignorance and learning not to speak*

Experiences of endometriosis were shaped by cultural expectations, gender norms, and taboos around discussing reproductive health. Participants described the pressures to stay silent about pain, menstruation, sexual health, or fertility, and how these pressures intersected with shame and self-doubt.

***Cultural silence around periods and pain.*** Participants spoke about their upbringing and the community norms that discouraged open discussion of menstrual or reproductive pain, positioning such experiences as private, shameful, or simply part of womanhood. These norms shaped how participants made sense of their symptoms from an early age, often limiting the language, permission, and confidence needed to speak about pain. As a result, early experiences of distress were frequently normalised or silenced within family and cultural contexts, laying the groundwork for delayed help-seeking and ongoing self-doubt in participants' narratives.

> *"In my culture, menstruation is viewed as impure and taboo. Sometimes it can be embarrassing to talk about symptoms, especially pain or heavy bleeding, which makes it difficult to ask for help." Mary*

Mary demonstrates cultural framing as a narrative feature, situating experiences within broader social norms and taboos. Structurally, the narrative links cultural expectations to personal consequences, showing how external beliefs shape the narrator's actions and emotions, in this case, the reluctance to disclose symptoms. The positioning of self in relation to these norms highlights relational identity, as the narrator negotiates personal experience against collective cultural pressures.

> *"I think culture plays a part in the fact that these things are very hush-hush and not discussed… but it's kept quiet and not really mentioned. I think it would be better to talk about these issues in society, because then people could get diagnosed earlier." Sienna*

Sienna highlights that relational and structural forces shape illness narratives. The narrative shows anticipatory meaning-making, as the participant links openness in cultural discourse to earlier diagnosis, suggesting an awareness of how narrative visibility could alter outcomes.

Participants frequently highlighted a lack of accessible, culturally relevant information about endometriosis, alongside broader taboos surrounding women's health within South Asian communities. Angelie reflected on this gap and its implications:

> *"I don't think I've seen information in Gujarati or Hindi or Punjabi on endometriosis. You know, you get heart disease and diabetes, but I think that would be good, in doctor's practices or women's health clinics. Our community needs to understand. But I think that it's a taboo subject, isn't it? Anything to do with women's health and menstruation, or, you know, like not being able to conceive, infertility. Nobody wants to talk about it, and women are made to feel, you know, like inadequate." Angelie*

In this account, Angelie explicitly identifies both the absence of culturally tailored resources and the presence of stigma, positioning these as interconnected barriers to understanding and support. The use of contrast (e.g., the availability of information on other conditions) highlights the relative neglect of endometriosis. The rhetorical question invites shared recognition. Importantly, this narrative moves beyond description to explanation, as Angelie links limited education and resource availability directly to ongoing stigma within the community. This reflects a broader pattern across accounts, where participants emphasised the need for more culturally accessible education and open dialogue around women's health, particularly in relation to menstruation and fertility. Participants felt that education needed to start early in schools and also extend out to the community (such as leaders and places of worship). It was felt that this would help tackle myths and increase awareness of endometriosis and women's health conditions.

***Gendered expectations and fertility pressures.*** Participants reflected on the cultural emphasis on early marriage and childbearing, and the emotional impact of endometriosis on meeting these expectations. This was reflected in how participants described external pressures from family and community, particularly within South Asian contexts.

> *"Even in this modern world, I think Asians generally have this expectation that every woman is going to bear children and be fertile… it's like everyone is asking, 'When are you going to have children?' or asking my mother-in-law, 'Any good news? Are you going to be a grandmother soon?' — that kind of cultural pressure." Angelie*

Angelie draws on reported speech to illustrate the persistence of these expectations, bringing social interactions into the narrative in a vivid and personal way. The use of repetition and rhetorical questioning emphasises the intensity and pervasiveness of this pressure. By

framing these expectations as ongoing and intrusive, the narrative conveys how cultural scripts around fertility are internalised and experienced as a significant emotional burden. Angelie goes on to explain how these external voices remained in her head:

> *"I had that at the back of my mind, that Asian in-laws, or the Asian community, would always think—would always point the finger—that it's something wrong with the woman."*

Amira adds to this perspective:

> *"I think it's because, in Asian culture, there's a lot of focus on women's fertility. There's even a word, barge it, which means infertile and is sometimes used as an insult toward Asian women. It's nothing my family would use, but it's very stigmatised and taboo. It feels like your worth as a woman is tied to your ability to have children. I even thought, 'Oh my God, what if I get married and can't have children?' It feels like it defines a part of who I am." Amira*

This demonstrates narrative positioning and cultural reflexivity as central features. Amira situates her personal experience within a broader cultural discourse around fertility and womanhood, highlighting how stigma and taboo shape self-perception. Structurally, the narrative uses internal reflection and direct thought to convey emotional intensity and the internalisation of societal expectations. The storytelling emphasises identity construction through cultural norms, showing how lived experience is filtered through both personal and collective narratives.

***Working hard to be believed.*** Several participants described feeling compelled to prove the legitimacy of their pain to family members, particularly within cultural contexts that prioritised deference to elders and collective decision-making. When relatives dismissed their symptoms as normal or exaggerated, participants often felt obliged to doubt their own bodily

knowledge. As a result, self-advocacy became not only a clinical struggle but also a familial one, requiring them to gather evidence, persist in their claims, and assert the credibility of their own lived experience within hierarchical family structures. This tension was particularly evident in participants, who balanced respect for hierarchy with emerging self-advocacy.

> *"I had to tell them about it. I had to prove that I had endometriosis and that it wasn't just normal women's problems. When I got my diagnosis, I was able to educate them on what endometriosis means, how it starts, and what it could lead to if it isn't treated early. That's what happened." Margaret*

Margaret enacts a reversal of epistemic authority, moving from being doubted to educating others about endometriosis. Agency under constraint is emphasised through the repeated phrase "I had to," highlighting the effort and necessity of self-advocacy, rather than this being a choice. The narrative follows a clear structural sequence from proving the illness to achieving authority. The repetition and the concluding statement provide narrative resolution, marking the shift from marginalisation to expertise.

***Unspoken Practices: Navigating Tradition.*** Some participants described engaging with unspoken or culturally informed health practices alongside biomedical care. These practices, including herbal remedies and specific dietary strategies, were often passed down through family or community knowledge. Narratively, they illustrate ways participants sought to manage symptoms when formal medical support was insufficient, while also negotiating the tension between respect for tradition and recognition of their limitations.

> *"Also, lots around herbal remedies and, yeah, eating particular foods to sort of help with your gut, which doesn't really help with your gut, but it's been passed down as kind of helpful knowledge. So I want to respect that and welcome it, but I don't want*

*to be overly enthusiastic about it because I don't want to lie like it's not solving my problems." Anaya*

A narrative tension emerges around engagement with culturally informed health practices. Some participants expressed respect for these practices but emphasised that they did not meaningfully address symptoms. Others actively sought out and valued this advice, framing it as a meaningful way to manage or understand their condition. This contrast highlights differing ways participants negotiated the role of tradition alongside biomedical care, reflecting broader tensions between cultural knowledge, personal experience, and medical authority.

*"…they've got different perspectives but they also live in different countries, so their view of healthcare might be different from ours…looking for alternative things like alternative medications, alternative remedies…my mum said, 'Have you thought about seeing a specialist, like acupuncture or something?'…At the beginning of my journey, I was like, nah, we're going the doctor route all the way. But listening to my mum and my mother-in-law…I've come to the opinion that there's no harm…so yeah, I'm just open to that" Sienna*

Sienna uses relational positioning, situating herself in relation to family members who offer traditional knowledge, and cultural reflexivity, reflecting on alternative remedies alongside biomedical approaches. There is clear narrative tension, as she negotiates between following the "doctor route" and exploring unspoken practices, while also negotiating epistemic authority between medical expertise and familial guidance. Temporal sequencing traces the evolution of their openness to these approaches, and reflective commentary provides insight into their reasoning, with an enumeration of different remedies highlighting the breadth of alternative strategies considered.

These narratives highlight how cultural expectations shaped not only family communication but also help-seeking, self-advocacy, and interactions with healthcare professionals. Silence was not merely interpersonal but structural, limiting access to knowledge, care, and validation. Throughout this overarching theme, participants describe their lives as being saturated with others' stories and interpretations, which often made it difficult for them to hold onto, trust, or prioritise their own viewpoints and embodied experiences.

***Resilience, growth and strength***

This theme reflects participants' accounts of resilience, coping strategies, and personal growth through living with endometriosis. Faith, spirituality, and self-advocacy were central to these narratives, alongside emotional, social, and cultural learning.

***Faith and spirituality as support.*** Participants described faith and spiritual practices as a vital source of strength, comfort, and resilience. Prayer, meditation, and reflection helped them cope with the emotional and physical challenges of endometriosis, offering a sense of grounding and purpose.

> *"From a Muslim faith perspective, as far as my understanding goes, we believe that life's tests and hardships come from God and are meant to bring us closer to Him. I've leaned on that belief at times, especially when I've questioned why I have this condition and what the meaning behind it is…That perspective has helped me make sense of periods and menstruation more positively. Given how Islam and Muslims are often portrayed in the media, I think it would be helpful if healthcare professionals understood how faith can support people in coping with chronic conditions. I wouldn't want religion to be misunderstood as something that promotes shame around menstruation, because it doesn't—it recognises it as a time of rest and recovery…For people living with chronic conditions like endometriosis, faith can be*

*what keeps you going during very difficult times. It's certainly something I've held on to," Aaliyah*

The storytelling emphasises faith as a resource for meaning-making and resilience, highlighting how external cultural and spiritual frameworks shape self-understanding and provide emotional support. There is also a didactic element, as the participant reflects on how healthcare professionals could better integrate awareness of faith into care.

Many participants described faith as an important source of coping and meaning-making. However, a narrative tension emerged for some, who felt that religious messages could reinforce silence around women's health, creating conflict between personal beliefs and culturally or religiously shaped expectations.

"*And I think it's just, it's not very fair how, like you can follow this religion and have such a strong faith and belief but then there are messages that you disagree with that apply to you and I 100% think that Women's Health isn't is like, not really seen as a good thing in religion." Yasmin*

Contrast is used to demonstrate the juxtaposition between what Yasmin believes and the reality of faith for herself. She locates herself within a religious framework while critically evaluating its impact on women's health. The narrative also uses evaluative language to highlight tension, showing how faith can simultaneously provide support and generate conflict.

***Resilience and coping strategies***. Participants highlighted the ways they developed resilience to navigate the ongoing challenges of endometriosis. Coping strategies ranged from practical approaches, such as pacing daily activities and seeking support, to emotional techniques like reflection, self-advocacy, humour and engaging in supportive communities.

*"But I feel like I turned it into a positive. Now I'm very knowledgeable about medicines—I make my own home antibiotics. When my child was sick, she recovered in two days. If I had relied on the GP, it would have taken 7 to 8 days for her to get better. I believe you can heal yourself." Ulima*

Ulima spoke of turning what she learnt into a positive in her day-to-day life. Ulima discusses repositioning of agency, presenting herself as knowledgeable, capable, and proactive in managing health, both for themselves and others. Structurally, the narrative emphasises cause-and-effect reasoning; their intervention led to faster recovery, highlighting competence and self-efficacy. The storytelling also reflects embodied and experiential knowledge as a legitimised epistemic resource, contrasting with reliance on formal medical authority. There is a transformative framing, turning past limitations or challenges into a source of empowerment and expertise. Ulima explicitly questioned the perceived supremacy of Western medicine, challenging its positioning as the ultimate authority on health and illness. After experiencing repeated disappointment within biomedical care, she described turning toward alternative frameworks as a source of hope and validation.

*"Yeah, I've talked about meditation, I've talked about prayers. I also do gentle exercises, I do yoga. Sometimes I just take a walk. My diet has changed too; it's not what I used to eat before, now that I've got a diagnosis. I eat more whole foods. Apart from medication, I tend to focus more on food, I do swimming, I take a walk. I've also been able to do deep breathing and sometimes I try to relax a lot to reduce stress, and I reduce the way I work." Laila*

Laila uses cause-and-effect framing, linking specific behaviours to stress and symptom management, which underscores practical, experiential knowledge as a narrative resource.

**Table 9.**
*Summary of narrative features used*

| Narrative Tool/Feature | Description/Function | Example from Data |
|---|---|---|
| **Temporal Sequencing** | Organises events over time, showing progression, delay, or escalation | Aaliyah: "it's been 11 years to get the diagnosis…" |
| **Reflective Evaluation** | Participant reflects on meaning, interprets events, or judges experiences | Aaliyah: "that's normal—for endometriosis that's normal when it shouldn't be" |
| **Meta-Narrative Commentary** | Reflection within the act of storytelling, generating insight | Aaliyah reflecting on abnormality of symptoms while narrating |
| **Identity Positioning** | How participants situate themselves (e.g., vulnerable, knowledgeable, self-advocate) | Ulima: "I position myself as young, lacking knowledge, and potentially flawed" |
| **Relational Positioning** | How others (professionals, family, peers) are positioned in relation to the participant | Zara: GP as validating ally; Aisha: professionals as dismissive |
| **Contrast / Moral Juxtaposition** | Highlights differences between experiences or expectations vs reality | Zara: supportive gynaecologist vs prior dismissive doctors |
| **Repetition / Narrative Anchors** | Repeated words or phrases to emphasise key experiences or tensions | Aaliyah: repetition of "normal" to emphasise tension between lived experience and societal assumptions |
| **Evaluative Language** | Explicit judgement of events, people, or systems | Sienna: "the mediator is very harsh…not very friendly" |
| **Listing / Accumulation** | Lists experiences, impacts, or examples to convey breadth or weight | Sienna: "stories, struggles, tips"; Laila: family dynamics, religious sensitivity, gender rules |
| **Physical Imagery / Metaphor / Simile** | Uses bodily or visual comparisons to convey pain or disruption | Ulima: "like knives are being stabbed into my stomach" |
| **Contrast Across Contexts** | Juxtaposition of experiences across time, location, or circumstances | Anaya vs Sienna: maternity vs cancer pathway to diagnosis |
| **Collective Narration / Peer Knowledge** | Situates participant within wider community or shared experience | Zara: online support groups as spaces to share stories and tips |
| **Causal / Reflective Linking** | Connects events, experiences, and consequences | Sienna: social invalidation leading to guarded behaviour and seeking genuine friendships |

**Summary**

The analysis revealed how participants' experiences of endometriosis are shaped by social, cultural, and medical contexts, producing a complex interplay between lived bodily experience and external responses. Across narratives, six interrelated themes were identified. Participants' stories consistently positioned pain as a narrative anchor, structuring accounts and providing a tangible reference point for the broader impact of the condition. There was consistent use of the external voice through participants' accounts, highlighting the impact those around them had on their experiences.

Narrative features and tools, including temporal sequencing, reflective evaluation, identity and relational positioning, repetition, physical imagery, and meta-narrative commentary, were used throughout to convey meaning, emphasise disruption, and highlight tensions between lived experience and external interpretations. These features illuminate the cumulative effects of medical dismissal, cultural expectations, and social invalidation, while also showing moments of validation, agency, and adaptation. Participants' narratives demonstrate that diagnosis, while providing explanation and relief, does not resolve uncertainty but prompts ongoing reflection, re-storying of the past, and engagement with an uncertain future. Overall, the findings foreground the intertwined roles of embodied experience, social context, and storytelling in shaping understanding, coping, and identity in the context of endometriosis.

# Chapter Five: Discussion

## Overview

This discussion chapter revisits the central aim of the research: To explore how South Asian Women experience a diagnosis of endometriosis in the UK. While the results chapter foregrounded participants' voices and their subjective interpretations, this chapter adopts a more interpretative and analytical stance. This chapter also draws on narrative typologies to aid interpretation. However, given critiques that typologies can oversimplify complex narratives, multiple typologies are considered. It is acknowledged that participants' stories may align with different typologies at different points in their narratives, while some experiences may not fit neatly within any single framework. The findings are discussed in relation to relevant psychological theories and existing research, while situating them within broader clinical and cultural contexts.

This chapter also critically evaluates the study's strengths and limitations, considers the clinical implications of the findings, and outlines recommendations for future research. It concludes with a reflexive statement reflecting on my position and role within the research process, with some reflexive commentary presented later and written in the first person.

## Summary of findings

Six themes and twenty-two subthemes were developed from participants' narratives: (1) "I knew something wasn't right: Early pain, confusion, and the normalisation of suffering, (2) I had to push": lack of clinicians' knowledge, self-advocacy and navigating the system, (3) Diagnosis as validation, and "now what?": Relief, anger, and searching for information, (4) "It's more than painful periods": Endometriosis as a whole-life condition and an "invisible disease", (5) "It's taboo": Cultural silence, shame, ignorance and learning not to speak, (6) Resilience, growth and strength (Table 8). Findings for each of the research aims are presented and discussed below.

***How do women from South Asian backgrounds experience their journeys to diagnosis?***

Participants often began their narratives by returning to menarche, retrospectively positioning it as the point at which pain and early signs of endometriosis were first present and situating it as the first "disruption". Following this, participants experienced normalisation and symptom minimisation by family members and healthcare professionals. Participants described repeatedly returning to health care professionals for help. For some individuals, this took place over a short period, while for others, it took years. For most, this became a cycle of repeatedly seeking help, only to be dismissed. Gergen and Gergen (1983) describe how narratives can take different trajectories, reflecting how individuals make sense of their experiences over time. While the overall narrative trajectories varied between participants, a common feature was the presence of a circular narrative, characterised by the repetition of certain story elements. In this study, the repetitive patterns were largely linked to participants' repeated interactions with GPs or healthcare professionals, during which their symptoms were dismissed or minimised. This repetition contributed to participants feeling "stuck" in their narratives, as experiences of invalidation reinforced ongoing uncertainty, frustration, and self-doubt. Participants positioned themselves as reliable knowers of their own bodies, yet lacking the legitimacy or language to have this knowledge recognised. The delay in diagnosis was therefore experienced not only as a medical issue but also as a prolonged period of epistemic injustice, where bodily pain was known but not believed.

Themes one ("I knew something wasn't right": early pain, confusion and the normalisation of suffering) and two ("I had to push": lack of clinicians' knowledge, self-advocacy and navigating the system) particularly illustrate this circularity, with narrative typologies of delayed recognition and normalisation of suffering recurring across accounts. The circular nature of these narratives highlights how systemic factors such as healthcare

dismissal, societal minimisation of women's pain, and cultural expectations can perpetuate cycles of delayed help-seeking and reinforce the internalisation of suffering. Frank's (1995) narrative typologies describe three common ways individuals make sense of illness: restitution, chaos, and quest; each reflecting different meanings, trajectories, and responses to living with ill health. Although the narrative trajectory appeared circular, when considered through Frank's narrative typologies (1995), these accounts may also reflect elements of chaos narratives, where experiences feel overwhelming, unresolved, there is a lack of control, and participants remain in search of answers. Recognising these patterns emphasises the importance of understanding chronic illness narratives not simply as linear journeys toward resolution, but as iterative processes shaped by repeated social, cultural, and institutional interactions.

Frank (1995) suggests that within chaos narratives, individuals can become caught in a self-perpetuating feedback loop, whereby the emotional impact of ongoing uncertainty and distress leads them to withdraw or "put their walls up," making it more difficult for others to engage with or support them. This process appeared evident within participants' accounts, where repeated experiences of dismissal and minimisation contributed to a gradual breakdown of trust in healthcare professionals and wider systems. As trust diminished, some participants became more guarded in their interactions, which may have further complicated communication and engagement with services.

For South Asian women, this erosion of trust may be further compounded by broader experiences of marginalisation within healthcare systems. Research suggests that individuals from minoritised ethnic backgrounds may already approach healthcare with caution due to previous experiences of discrimination, cultural misunderstanding, or not being believed (DHSC, 2022; NHS Race and Health Observatory, 2022). Within this context, repeated dismissal of symptoms may reinforce pre-existing mistrust, intensifying disengagement and reluctance to seek help. This aligns with wider literature on systemic and institutional racism

in healthcare, which highlights how inequities in treatment and representation can shape patient experiences and expectations of care (Nazroo, 2003; Williams, 1999). As such, the feedback loop described within chaos narratives may be particularly pronounced for South Asian women, where interpersonal experiences with clinicians intersect with broader structural inequalities, further entrenching feelings of isolation and disconnection from care.

As well as being dismissive, GPs were described as lacking sufficient knowledge about endometriosis, which was perceived as contributing to delays in diagnosis. GPs were often positioned as holding epistemic authority and acting as gatekeepers to care, controlling access to investigations and treatment. Some participants described strategies to "play the system," highlighting their awareness that obtaining recognition for their symptoms required navigating these power dynamics effectively. This aligns with Frank's (1995) concept of individuals striving to be "good stories" for their clinicians, where patients shape their narratives to gain validation and access to care. While this strategy sometimes facilitated access to care, it also had consequences: participants reported emotional exhaustion, frustration, and moments of self-doubt when their stories were minimised or dismissed. Moreover, the need to fit their experiences into a socially acceptable narrative meant that some aspects of their suffering were left unspoken, highlighting how the work of being a "good story" can constrain authentic expression and shape how individuals understand their illness and agency. Participants' interactions with GPs and other healthcare professionals also suggest that healthcare provision within the UK continues to operate largely within a biomedical model, which prioritises clinical expertise and positions medical professionals as the primary authorities on illness. Within this framework, doctors' voices are often privileged in decision-making processes, potentially limiting the recognition of patients' experiential knowledge and shaping how symptoms are interpreted and addressed within clinical encounters.

Over time, the dismissal experienced caused many to internalise these responses and doubt the legitimacy of their own symptoms. The internalisation of self-doubt reported by participants can be understood through multiple psychological theories emphasising the social construction of self-belief. From a symbolic interactionist perspective, individuals develop their self-concept partly through others' responses to them (Mead, 1934); when healthcare professionals and family members repeatedly dismiss symptoms, individuals may begin to question their own embodied experiences and self-trust. Patient-doctor communication theory (Street et al., 2009) adds to our understanding of this, suggesting that when communication is dismissive or lacks validation, patients may feel their concerns are not credible, which can undermine confidence in their own bodily knowledge and discourage further help-seeking. In relation to South Asian women, this suggests that dismissive or non-validating communication may have a compounded impact, as it interacts with existing cultural norms around silence, stigma, and deference to authority. When healthcare professionals do not validate symptoms, this may reinforce prior messages from family or community that such pain is “normal” or not to be spoken about, further undermining women’s confidence in their own embodied knowledge. As a result, South Asian women may be less likely to re-present or advocate for themselves, particularly in contexts where questioning authority is discouraged, leading to prolonged delays in help-seeking and access to care.

Chronic invalidation has also been linked to reduced self-esteem and psychological distress in invisible illness populations (Ames & Renn, 2021; Reynolds & Donaldson, 2007). This can be understood as consistent with Goffman’s (1963) notion of internalised stigma, where individuals come to accept and incorporate negative societal beliefs or stereotypes about a condition into their own self-concept. Rather than stigma existing only externally, it becomes internalised, shaping how individuals perceive themselves and their experiences. In the context of endometriosis, this may mean that participants begin to view their pain as something to

minimise, hide, or feel ashamed of, particularly when it is repeatedly dismissed or framed as "normal." Over time, this internalisation can lead to reduced self-worth, increased self-doubt, and reluctance to seek help. For South Asian women, this process may be further intensified by cultural norms around modesty, silence, and stigma surrounding menstruation and reproductive health, reinforcing the tendency to downplay symptoms and avoid disclosure (e.g. Knight et al., 2014; Wilson et al., 2022).

Furthermore, elements of learned helplessness (Maier & Seligman, 1976) may emerge when repeated dismissal reinforces a sense of lack of control over one's health, contributing to diminished agency and increased self-doubt. These frameworks collectively suggest that social responses to symptoms can shape not only illness behaviour but also identity, self-esteem, and long-term adjustment to chronic health conditions. Ideas from Adjustment Theories (Taylor, 1983) suggest invalidation can disrupt how individuals make sense of and adapt to chronic illness, complicating the process of recognising, accepting, and responding to their condition. Given the increased risk of individuals with endometriosis developing further mental health difficulties (Szypłowska et al., 2023), this highlights the need for revision within the healthcare system so that interactions are supportive and do not further perpetuate difficulties.

Explanations for the dismissal and minimisation of symptoms reported by participants were multifaceted. Some attributed these experiences to systemic failures, including underfunding of the NHS and limited resources for women's health. Others highlighted how gendered and racial biases intersected with these structural issues, where being a woman and South Asian compounded barriers to recognition and care, with some participants describing

experiences consistent with "Bibi syndrome,"[2] reflecting culturally specific stereotypes. From a whiteness lens, this can be understood not simply as individual bias, but as a reflection of how healthcare systems are structured around white, Western norms that position certain bodies, behaviours, and ways of communicating distress as more credible than others. Within this framework, whiteness operates as the invisible standard against which all patients are assessed, meaning that expressions of pain or help-seeking that fall outside of this norm may be misinterpreted, minimised, or dismissed.

For South Asian women, this may result in their symptoms being filtered through racialised and gendered assumptions, such as being perceived as exaggerating, overly emotional, or culturally predisposed to certain behaviours. These interpretations can undermine their epistemic authority as knowers of their own bodies, contributing to unequal care. Importantly, this lens shifts the focus away from individual interactions alone and towards the broader structural context, highlighting how institutional norms and practices may reproduce inequities in recognition, diagnosis, and treatment.

Moreover, from an intersectionality perspective (Crenshaw, 1991), these accounts illustrate how multiple social identities, gender, ethnicity, and migration background, interact with systemic inequalities to shape access to healthcare and the legitimacy of patients' embodied knowledge- patients felt that had they been white, or male or white and male, their experiences would have been different. Together, these perspectives highlight how structural, cultural, and social biases converge to produce disparities in diagnosis, treatment, and validation, emphasising the importance of culturally informed, equity-focused healthcare for

[2] A derogatory and racialised stereotype reported within some UK healthcare contexts in which South Asian women's symptoms are characterised as exaggerated or psychosomatic rather than clinically legitimate (Sheikh, 2022).

women with endometriosis. Participants also highlighted that, despite many difficult experiences, positive encounters with healthcare professionals had a meaningful impact. They emphasised that the actions of a single supportive clinician could alter the trajectory of their story and ease the emotional burden they were experiencing. Being validated and heard was particularly powerful, often enabling participants to move out of the chaos narrative and regain a sense of control and legitimacy over their experiences.

Due to feeling that access to services was limited, many described being their own doctors, self-managing symptoms, and becoming their own advocates. Although during the interviews, participants were able to view this as a new strength, at the time, it was perceived as a burden and as being abandoned by the healthcare system. Many participants also described turning to private care due to desperation and not being able to wait due to the chronic pain and the nature of their endometriosis. As discussed, endometriosis is widely recognised as a chronic pain condition (Horne & Missmer, 2022). Consistent with this, pain emerged as the central organising feature of participants' narratives, repeatedly shaping their accounts as they sought explanation, legitimacy, and recognition. From a narrative perspective, this reflects how individuals structure illness stories around the most disruptive elements of their experience (Frank, 1995), with pain becoming the key point through which participants attempted to make sense of their condition. The emphasis on pain also appeared linked to participants' efforts to gain validation within healthcare interactions, aligning with patient-doctor communication theories that highlight the importance of legitimising patients' experiences in clinical encounters (Street et al., 2009). Furthermore, the need to repeatedly justify pain can be understood through stigma and invalidation frameworks (Goffman, 1963), where individuals with invisible or poorly understood conditions must provide evidence of suffering to have their experiences recognised. In this context, pain took on not only a physical meaning but also

moral and relational significance, shaping how participants explained absence, justified help-seeking, and challenged dismissal from others.

The tendency for participants to turn to private healthcare, often in response to prolonged NHS waiting times or repeated experiences of dismissal, highlights broader structural inequalities within endometriosis diagnostic pathways. While this shift was frequently described as a turning point that enabled participants to regain a sense of agency in seeking care, it was also simultaneously framed as an act of necessity rather than genuine choice. These findings can be understood through an intersectional framework, which recognises that healthcare experiences are shaped by overlapping systems of inequality, including gender, ethnicity, and socioeconomic position (Crenshaw, 1989). Importantly, the ability to navigate or circumvent systemic barriers through private healthcare is not equally available across all populations. For South Asian women and other racialised groups, access to private care may be constrained by wider structural inequalities, including income disparities and unequal access to financial resources (Nazroo, 2020). Consequently, the increasing reliance on private healthcare within participant narratives raises important equity concerns, as timely diagnosis and treatment may become increasingly dependent upon economic capital rather than clinical need. This reflects wider concerns regarding the emergence of a two-tier healthcare system, in which already marginalised groups may face compounded barriers to accessing appropriate endometriosis care (Department of Health and Social Care, 2022). Within this context, participants' narratives of agency should therefore be understood not solely as individual acts of empowerment, but also as responses to structural inadequacies within public healthcare provision.

Consistent with previous research, participants reported that receiving a formal diagnosis provided relief by giving a name to their experiences (theme 3: Diagnosis as validation, and now what? Relief, anger, and the search for information) (e.g. Ballard et al.,

2006). However, for many, it also brought up feelings of anger that they waited so long, and diagnosis marked the start of a new adjustment process, requiring them to renegotiate their understanding of symptoms, identity, and strategies for managing the condition. This ongoing adaptation was complicated by the limited treatment options available, with interventions often focused on hormonal manipulation rather than holistic symptom management. Participants expressed frustration at the gendered disparities they perceived in healthcare, noting that endometriosis research and treatment are underfunded compared with conditions affecting men, leading to fewer options and less effective pain management. As discussed in the introduction, the feminist movement highlights these experiences reflecting broader structural inequities in medical knowledge production and healthcare delivery, where women's pain has historically been minimised, under-researched, and undervalued (Sen & Östlin, 2008; Ussher, 2006). Recognising these systemic issues highlights the need for healthcare and research practices that validate WAFAB experiences and address structural barriers to equitable care.

Participants also described seeking information independently, but frequently encountered resources that did not reflect their experiences as South Asian women or the specific challenges they faced. These experiences align with the narrative typology of "searching for representation," in which individuals actively seek knowledge about their condition, encounter resources that fail to reflect their cultural or lived experiences and perceive the rare moments of recognition or representation as particularly significant. This highlights how the absence of culturally tailored information not only limits understanding and coping but also shapes the meaning and emotional impact of living with endometriosis within racialised communities. These experiences align with the "snowy white peaks" metaphor (Kline, 2014), highlighting how healthcare knowledge and resources are often structured around majority populations, marginalising racialised patients. From an institutional racism perspective, this reflects systemic inequities in the production and dissemination of health

information, where structural biases limit access to tailored guidance, support, and validation for women from racialised communities, creating another barrier to care.

Participants described endometriosis as a whole-body condition that affected nearly every aspect of their lives, challenging the common perception of the condition as simply a "painful period" (theme 4: "It's more than painful periods": Endometriosis as a whole-life condition and an invisible disease). Many highlighted that endometriosis is frequently misunderstood and minimised by others, which compounded the difficulties of managing the condition. As well as impacting relationships and work, it also impacted identity and functioning. This aligned with Frank's (1995) idea of the "body problem", where illness undermines a person's sense of control and certainty over their body, making it feel unpredictable and unfamiliar, which can disrupt identity and challenge cultural ideals of independence, productivity, and autonomy.

Beyond the physical symptoms, participants described significant psychological impacts such as low mood and anxiety (theme 4: "It's more than painful periods": Endometriosis as a whole-life condition and an invisible disease). Several participants also disclosed experiencing suicidal thoughts. These accounts echo previous research suggesting that endometriosis is associated with an increased risk of mental health difficulties (Szypłowska et al., 2023; Thiel et al., 2024), with anxiety and depression among the most commonly reported concerns (Delanerolle et al., 2021). However, unlike much of the existing literature, participants in this study were able to provide insight into the factors that contributed to or exacerbated these emotional difficulties, which in part may be due to the narrative analysis approach. Pain emerged as a key driver of distress, reinforcing earlier findings in this study that pain functioned as a central organising feature of participants' narratives. Chronic and unpredictable pain has been widely recognised as having profound psychological consequences, often affecting mood, identity, and daily functioning (Nicholas et al., 2019). In

addition to pain, participants described feeling misunderstood by friends, family, and partners, which further intensified emotional distress. Many also reported experiencing social isolation, as the demands of managing their symptoms limited their ability to participate in social, relational, and occupational activities. Together, these findings highlight the complex interplay between physical symptoms, interpersonal relationships, and psychological well-being in shaping the lived experience of endometriosis.

From the perspective of ecological systems theory (Bronfenbrenner, 1979), these experiences can be understood as the result of multiple interacting systems. The impact on personal relationships and work reflects influences at the microsystem level, while societal minimisation of menstrual health and chronic pain represents broader cultural and institutional factors within the macrosystem. This framework helps to illustrate how individual experiences of endometriosis are shaped not only by the physical symptoms themselves but also by the social, relational, and cultural contexts in which individuals live. This interpretation is consistent with recent chronic pain literature, which conceptualises adjustment and acceptance as occurring within an interconnected ecosystem of personal, interpersonal, healthcare, sociocultural, and political influences (MacGregor et al., 2024). Together, these perspectives highlight the importance of understanding endometriosis as an experience that is shaped by multiple interacting systems rather than solely by individual symptoms or coping processes.

Participants often described their journey to diagnosis, and the experiences that followed, as contributing to a sense of resilience (theme 6: Resilience, growth and strength). Many reported becoming highly knowledgeable about endometriosis, educating others about the condition, and adapting aspects of their lives through changes to exercise, diet, and daily routines, alongside developing strategies to manage the emotional challenges associated with the illness. These accounts resonate with Frank's (1995) quest narrative, in which illness is reframed as an experience that generates insight, meaning, or personal transformation. Through

this lens, participants' efforts to advocate for themselves and others, and to reconstruct their lives around the condition, can be understood as attempts to create meaning from a prolonged and difficult diagnostic journey.

However, the concept of resilience has also been widely critiqued within health and social research. Scholars argue that resilience narratives can sometimes obscure structural barriers by promoting individual strength rather than the systems that produce or maintain suffering (Ungar, 2011; Luthar et al., 2000). For many participants, resilience appeared less as a deliberate pursuit and more as a necessity arising from repeated experiences of dismissal, delayed diagnosis, and limited treatment options. Interpreting these accounts through intersectionality theory (Crenshaw, 1991) further highlights how resilience is shaped by overlapping social identities and structural inequalities, including gender, ethnicity, and migration history. Participants from South Asian backgrounds described navigating additional cultural and systemic challenges within healthcare systems that do not always recognise or represent their experiences. This dynamic also resonates with the "snowy white peaks" metaphor (Kline, 2014), which illustrates how healthcare knowledge, leadership, and research are often centred around majority populations, leaving minoritised groups underrepresented in both evidence and services. Within this context, participants' narratives of resilience may reflect not only personal adaptation but also the additional labour required to navigate systems that were not designed with them in mind. Taken together, these findings suggest that while elements of the quest narrative were present, resilience should not be interpreted solely as an individual strength. Rather, it emerges within broader structural contexts that shape whose voices are heard, whose suffering is recognised, and whose health needs are prioritised. Recognising this tension is important to avoid romanticising resilience and instead foreground the systemic changes required to improve care for individuals living with endometriosis.

***How do cultural, familial, and community contexts influence the meaning-making of endometriosis?***

This study offers a novel empirical contribution to the literature by providing insight into how endometriosis is experienced and understood by South Asian women. A notable narrative feature within participants' accounts was the use of an external voice or narrator when describing their experiences. Across narratives, participants highlighted how multiple voices, including those of healthcare professionals, family members, and wider community expectations, shaped how they interpreted their symptoms and navigated their illness journeys. From a narrative perspective, illness experiences are not constructed in isolation but are socially shaped through dialogue with others and the cultural stories available to individuals (Frank, 1995). In this study, these external influences played a significant role in shaping participants' interpretations of their symptoms, their help-seeking behaviours, and the meaning they attributed to endometriosis. Participants frequently described growing up in environments where community and family norms discouraged open discussion of menstrual or reproductive pain, framing such experiences as private, shameful, or simply part of being a woman (theme 2: "I knew something wasn't right": Early pain, confusion, and the normalisation of suffering; theme 5: "It's taboo": Cultural silence, shame, ignorance and learning not to speak). These norms influenced how participants understood their symptoms from an early age, often limiting the language, permission, and confidence needed to articulate pain. As a result, early experiences of distress were frequently normalised or silenced within family and cultural contexts, contributing to delayed help-seeking and the development of ongoing self-doubt in participants' narratives. This reflects how meaning-making around illness is socially constructed through interactions with others and shaped by broader cultural narratives. Such dynamics are particularly important to consider within South Asian communities, where family and community structures often play a central role in shaping beliefs and behaviours (Afshar,

1989; Wilson, 2006). In these contexts, the perspectives of those in positions of authority within the family or community may be prioritised, sometimes at the expense of individuals' own embodied knowledge. For participants in this study, this dynamic appeared to contribute to an erosion of self-trust and confidence in their own bodily experiences.

Family structures and cultural expectations also influenced participants' healthcare decision-making. In many South Asian communities, collectivist cultural values emphasise interdependence, family cohesion, and prioritising the needs of the group over those of the individual (Hofstede, 2001; Triandis, 1995). Within such contexts, health decisions may be negotiated collectively rather than individually. Participants described instances where family members influenced or determined whether they pursued medical investigations or treatment, which at times contributed to delays in seeking care. Over time, however, participants' narratives reflected a shift as the severity and persistence of symptoms became increasingly difficult to ignore, prompting many to prioritise their own health needs. Notably, participants who were born in the UK appeared to reach a sense of agency in their healthcare decisions more quickly than those who had migrated from South Asian countries, suggesting that migration history and differing cultural contexts may influence how individuals negotiate autonomy within collectivist family systems.

Migration experiences also appeared to shape how participants interpreted and engaged with healthcare services. Participants who had migrated to the UK often described comparatively fewer negative perceptions of healthcare interactions, reflecting that access to gynaecological care had been limited or unavailable in their countries of origin. While this was not universal, it aligns with broader research on migrant health, suggesting that prior healthcare experiences influence expectations, help-seeking behaviours, and engagement with new systems (Giorgi et al., 2022). Participants who had experienced restricted access to care previously often expressed relief at being able to access diagnostic investigations and treatment

options within the UK, even when barriers such as dismissal or limited specialist knowledge persisted. This pattern resonates with the "grateful immigrant" narrative described by Ghosh (2021), in which migrants may view healthcare opportunities more positively due to previous structural limitations.

Participants' meaning-making processes were influenced not only by personal experiences of symptoms (microsystem), but also by family dynamics and healthcare interactions (mesosystem), alongside broader cultural norms and healthcare structures (macrosystem). For example, at the microsystem level, individuals described experiencing severe and persistent pain that they themselves recognised as abnormal. However, within the mesosystem, family members often normalised these symptoms as a typical part of womanhood/ menstration, while healthcare professionals at times dismissed or minimised concerns, shaping how participants interpreted and responded to their experiences. At the macrosystem level, wider cultural norms around menstruation as a taboo topic, alongside structural issues within healthcare such as limited awareness of endometriosis and gendered biases, further reinforced these interpretations. Together, these interconnected systems influenced how participants understood their symptoms, often contributing to delays in help-seeking, internalised doubt, and challenges in navigating care.

From an Adjustment Theory perspective (Taylor, 1983), differing expectations of healthcare may also shape how individuals appraise and adapt to chronic illness. For migrants, previous limited access to care may initially frame healthcare encounters more positively, whereas individuals born within the UK healthcare system may experience greater frustration when expectations of care are not met. These differences highlight how cultural and structural contexts shape the ways individuals interpret and respond to illness experiences.

Religion also emerged as an important influence on how participants made sense of their experiences. For many participants who actively practised their faith, religion was described as a source of strength, comfort, and guidance during difficult periods. Religious practices such as prayer or meditation were perceived as helpful in coping with symptoms and managing emotional distress. Some participants reframed their experiences through spiritual interpretations, describing endometriosis as a test, part of God's plan, or a challenge that could lead to personal growth. In this way, faith provided a framework through which participants could find meaning and maintain hope despite ongoing uncertainty.

However, an important tension emerged between religion and cultural norms. While faith was often experienced as empowering and supportive, cultural expectations within families and communities were more frequently described as reinforcing silence around menstruation and reproductive health. Participants described how cultural norms discouraged open discussion of symptoms, which sometimes delayed recognition of the seriousness of their condition. This distinction suggests that while religion could facilitate meaning-making and resilience, cultural practices surrounding gender and bodily privacy could simultaneously constrain communication and help-seeking. Together, these findings highlight the complex ways in which cultural, familial, and community contexts interact to shape how South Asian women understand, negotiate, and respond to endometriosis. The next subsection will go on to situate these individual accounts within broader religious and cultural frameworks around motherhood, obligation and women's roles.

***How do intersecting identities shape experiences of validation, dismissal, or support within healthcare encounters?***

Some of the findings related to this aim overlap with those explored in the previous section, as several findings were relevant across multiple areas of the analysis. However, other findings were more specifically related to the focus of this research aim. This subsection

therefore extends the earlier analysis while also introducing additional insights that were particularly salient to this area of the research. For many participants, experiences of endometriosis were shaped by intersecting factors such as culture, gender, family expectations, and migration history (theme 5: "It's taboo": Cultural silence, shame, ignorance and learning not to speak). These experiences can be interpreted through Frank's (1995) restitution narrative, in which illness is framed as a temporary disruption to be corrected. Cultural and familial pressures around childbearing, fertility, marriage, and fulfilling social roles meant that the desire to "return to normal" was not only personal but also socially mediated. Delays in diagnosis or access to care heightened tension between participants' embodied experiences and these external expectations, contributing to frustration, guilt, and feelings of inadequacy. Participants also reported that opportunities for cure or relief were often tied to reproductive milestones, for example, being told symptoms might improve after having children, revealing that the possibility of wellbeing was frequently conditional on meeting cultural or gendered expectations.

Several participants described childbearing as both a duty and a source of fulfilment, which added further complexity to their narratives. These findings align with previous research showing that social pressures around motherhood are particularly salient for South Asian women with endometriosis (Denny et al., 2011) and may also be linked to broader cultural imperatives such as upholding family reputation (Afshar, 1989; Wilson, 2006). More recent work supports the idea that cultural and religious ideologies create intersecting pressures that intensify both the physical and psychological burden of the condition (Wilson et al., 2022). Applying intersectionality theory (Crenshaw, 1991) helps illuminate how overlapping social identities and power structures, including gender, culture, and family dynamics, simultaneously shape illness experiences, meaning-making, and coping strategies, highlighting the importance of considering multiple, intersecting influences on health and wellbeing.

Above, Frank's (1995) narrative typologies have been used to analyse participants' experiences, but they have been applied in conjunction with other theoretical frameworks, including intersectionality theory (Crenshaw, 1991) and ecological systems theory (Bronfenbrenner, 1979), to better capture the complexity of experiences. It is important to recognise that Frank's typologies alone may not fully represent the diversity and nuance of every participant's story. Critics have highlighted that typologies risk oversimplifying illness narratives by fitting varied experiences into predefined categories (Bury, 2001; Riessman, 2002). Additionally, when thinking from a PCF perspective, Frank is a male author; his conceptualisations of illness and embodiment may not fully reflect women's lived experiences, particularly for conditions like endometriosis that are uniquely gendered (Kleinman, 1988). Moreover, Frank's typologies centre on individual meaning-making, which reflects Western ideals of autonomy. PCF argues that this overlooks collectivist contexts (e.g., family, community, religion), which are central for many South Asian women (Mohanty, 2003). Part of the challenge of analysing this study is that there are currently no theories developed specifically to understand the experiences of South Asian women with endometriosis, making it necessary to interpret the findings through a combination of existing theories while remaining critically aware of their limitations. Furthermore, as discussed previously, "South Asian" is a broad term encompassing diverse cultures, religions, and national backgrounds, with experiences that may differ substantially. Using multiple theoretical perspectives is therefore key to capturing as many aspects of these varied experiences as possible.

**Findings in Relation to Existing Literature**

Although no studies to date have specifically explored the experiences of South Asian WAFAB with endometriosis in the UK, there is a substantial body of literature examining the experiences of women more broadly. As outlined in the introduction, Pettersson and Berterö's (2020) systematic review found that healthcare professionals often demonstrated limited

knowledge of endometriosis and frequently failed to validate patients' concerns. The review also highlighted that clinicians' attitudes, particularly their willingness to listen, learn, and provide support, played a central role in shaping individuals' experiences and contributed to the often prolonged and distressing diagnostic journey. These findings are consistent with those of the present study.

Similarly, Young et al. (2015) identified that endometriosis impacts multiple areas of life, including relationships, employment, social functioning, medical interactions, symptom burden, and fertility. These multidimensional impacts were also evident within the current study. Furthermore, the meta-ethnographic synthesis presented in Chapter Two highlighted key challenges within UK healthcare experiences, including delayed diagnosis, dismissal and minimisation of symptoms, communication barriers, and difficulties in help-seeking. While these categories broadly align with the findings of the present study, important differences emerged.

For example, the theme of dismissal and minimisation of symptoms closely reflects the findings of medical normalisation and dismissal identified in this study. However, participants here described additional, more nuanced explanations for these experiences, including the role of racial stereotyping. Some participants felt that their South Asian background contributed to perceptions that they were exaggerating their symptoms, suggesting that dismissal was not solely related to gaps in clinical knowledge but also shaped by racialised assumptions. This highlights how shared experiences of dismissal may be underpinned by distinct mechanisms for different groups.

Similarly, while previous research has identified communication barriers and difficulties articulating pain, this study extends these findings by situating such challenges within cultural contexts. Participants described how cultural silence around menstruation

limited their ability to develop the language needed to describe their symptoms, with discussions often constrained by shame and stigma. As such, communication difficulties were not only interpersonal but also shaped by broader cultural norms.

The findings of this study also align with research focusing specifically on South Asian populations. For instance, Denny et al. (2011) found that painful menstruation was often normalised among South Asian participants. In the present study, participants similarly reported being told their symptoms were "normal," leading to an initial internalisation of this narrative. However, this study extends previous findings by highlighting that many participants simultaneously held a sense that something was wrong, reflecting a tension between external narratives and embodied knowledge.

Finally, Hudson et al. (2016) highlighted how cultural expectations around marriage, fertility, and gender roles shape how individuals interpret and respond to endometriosis. The current study builds on this by demonstrating how these expectations can impact women's sense of identity, contributing to emotional distress. For many participants, childbearing was framed not only as a cultural expectation but also as central to womanhood, creating additional psychological burden when this was challenged by the condition.

Overall, while the findings of this study align with existing literature, they also extend current understanding by highlighting the culturally specific and intersectional factors that shape the experiences of South Asian women with endometriosis.

**Clinical Implications**

Given that the findings of this study align with existing research on endometriosis, this section outlines the clinical implications, highlighting both general considerations for individuals with endometriosis and specific recommendations to address the unique needs of South Asian women.

This research highlights endometriosis as a chronic, long-term condition that often begins in early adolescence, emphasising the importance of timely recognition and intervention within healthcare services. Healthcare professionals should ensure that clinical practice aligns with NICE guidance, which recommends that individuals presenting with persistent symptoms suggestive of endometriosis be referred to specialist gynaecology services even when initial imaging results are inconclusive (NICE, 2017). The findings of this study suggest that individuals presenting with symptoms suggestive of endometriosis during adolescence or early adulthood should be taken seriously and offered appropriate investigation and referral pathways to reduce delays in diagnosis and treatment, as highlighted by the House of Commons Women and Equalities Committee (2024). This means referring young WAFAB to gynaecology or for additional scans when symptoms indicative of endometriosis first present.

As highlighted by ecological systems theory (Bronfenbrenner, 1979), an individual's experience of illness is shaped not only by their biology but also by interactions with family, community, and healthcare systems. Current NICE guidelines for endometriosis primarily adopt an individualistic approach and may not fully consider how experiences and treatment needs differ across cultural contexts. For example, pain may be expressed through somatisation, which is more common in South Asian and other non-Western populations (Raguram et al., 2001). Consequently, assessment and management of endometriosis-related pain in South Asian women may require culturally sensitive approaches, including awareness of how cultural norms influence symptom expression and health-seeking behaviours. Therefore, NICE guidelines could be strengthened by explicitly addressing the need for culturally informed care, including less individualistic approaches and recognising how family, community, and cultural norms shape symptom expression, help-seeking, and treatment experiences.

Clinicians should also be aware of the language they use during consultations, ensuring they use clear anatomical terminology rather than colloquial or slang expressions. They should also be conscious of the power dynamics that may exist within healthcare encounters. Participants' accounts suggest that medical interactions can reinforce hierarchical relationships, where clinicians are seen as the primary authorities on illness, while patients' experiential knowledge might be overlooked. Adopting a more collaborative and patient-centred approach that values patients' embodied experiences could help foster trust and improve communication. Cultural and familial contexts should also be considered during clinical encounters. In some cases, family members may attend appointments and play an influential role in healthcare decision-making, particularly for individuals from collectivist cultures, such as South Asian women. Clinicians need to remain attentive to these dynamics and ensure patients have the opportunity to speak openly about their symptoms and concerns. Offering patients the choice of consultations with female clinicians may be especially important for South Asian women, as cultural or religious beliefs around modesty and gender norms can make discussing sensitive gynaecological symptoms with male clinicians difficult. Providing this option can help create a safer, more supportive environment, encouraging open communication, accurate reporting of symptoms, and prompt help-seeking.

Additionally, the findings highlight the potential value of advocacy services within endometriosis care pathways. Providing access to trained advocates could support individuals in attending appointments with someone they feel comfortable with, particularly when discussing sensitive or culturally stigmatised topics. Advocates may also help bridge communication gaps by supporting patients to articulate their experiences, while being mindful of cultural context and potential barriers to self-expression. This may be especially beneficial for individuals who find it difficult to navigate healthcare interactions independently and could help promote more equitable and patient-centred care.

**Policy implications**

The findings of this study also highlight several important implications for healthcare policy and service provision. Greater investment in training and education for GPs and other healthcare professionals is needed to improve awareness and recognition of endometriosis and other women's health conditions. Earlier identification of symptoms and more timely referral pathways may help reduce diagnostic delays and improve both physical and psychological outcomes for patients.

In addition, there is a need for the development of more holistic and multidisciplinary care pathways for individuals living with endometriosis. Such pathways should integrate medical treatment with broader forms of support, including physiotherapy, dietary advice, education, and psychological services, in order to address the complex biopsychosocial impact of the condition.

The findings highlight a reported breakdown of trust in public services among participants. Investing in grassroots and community-based organisations may therefore be particularly beneficial, as these services are often better positioned to engage individuals in culturally sensitive and trusted ways (Viswanathan et al., 2010). For South Asian women with endometriosis, grassroots organisations may provide more accessible and relatable support, helping to bridge gaps between communities and formal healthcare systems. This approach may support the rebuilding of trust, encourage engagement with services, and create safer spaces for individuals who may otherwise feel hesitant to seek help.

Policy changes are also required to improve the accessibility and cultural relevance of healthcare information and services. Participants described difficulties accessing information that reflected their experiences as South Asian women, such as addressing how to discuss difficulties with family, the impact on expectations with marriage, or information where the

person photographed or delivering the information looked like them. Healthcare resources should therefore be developed in ways that are culturally sensitive and available in multiple languages to ensure that diverse communities are adequately represented and supported. Improving inclusivity in health information and service provision may help reduce feelings of isolation and improve engagement with healthcare services among minoritised groups.

Taken together, these implications highlight the importance of developing healthcare systems that are responsive to the diverse needs of patients living with endometriosis. The experiences described in this study suggest that cultural context, gendered expectations, and racialised inequalities can shape how symptoms are interpreted, communicated, and responded to within healthcare settings. Addressing these disparities requires not only improvements in clinical knowledge and service provision but also greater attention to cultural competence, representation, and equity within healthcare policy and practice. By recognising the specific barriers faced by South Asian women and other minoritised groups, healthcare services may be better positioned to provide more inclusive, responsive, and equitable care for individuals living with endometriosis.

**Psychological Implications**

Guidelines from NICE further recommend that individuals experiencing chronic pain should have access to multidisciplinary pain management services, including psychological support such as cognitive behavioural therapy (CBT), acceptance and commitment therapy (ACT), and mindfulness-based approaches (NICE, 2021). These interventions aim to support individuals in developing coping strategies, reducing distress associated with pain, and improving overall functioning. However, the findings of this study suggest that psychological support for individuals with endometriosis must be delivered carefully so that it does not inadvertently minimise or psychologise symptoms, particularly given participants' prior experiences of dismissal. Pain emerged not only as a physical symptom but also as something

with moral, relational, and social meaning, shaping how participants justified help-seeking, navigated interactions with healthcare professionals, and managed expectations within family and cultural contexts. Psychological interventions should therefore adopt a holistic and culturally informed approach, recognising the multiple ways pain is experienced and understood. Attending to these broader dimensions may help clinicians validate patients' experiences while supporting more meaningful engagement with treatment.

## Strengths and Limitations

### *Grouping*

A key strength of this study is that it is, to the researcher's knowledge, the first to focus specifically on the experiences of South Asian women living with endometriosis in the UK. This is particularly important given emerging evidence suggesting that endometriosis may be prevalent within this population and that South Asian women can face additional challenges within healthcare systems due to wider health inequalities. By centring the voices of South Asian women, the study begins to address a notable gap in the literature and provides important insight into how cultural background, identity, and social context may shape experiences of diagnosis, care, and living with the condition.

At the same time, the study grouped South Asian participants together, which may obscure differences within this diverse population. Some variations were observed between participants who were born in the UK and those who migrated to the UK, suggesting that migration history and cultural context may influence experiences. However, given the small sample size, these observations cannot be generalised.

### *Recruitment*

Most participants were recruited through social media, with a smaller number recruited from support groups. Individuals who engage with these networks may do so due to limited

personal support, meaning their accounts may reflect more challenging experiences (van der Zanden et al., 2022; Whitaker et al., 2017). As a result, the findings may be shaped by the perspectives of individuals seeking external support and may not fully represent the experiences of those who do not engage with such communities. At the same time, recruiting through these networks enabled access to participants who were already engaged in reflecting on and discussing their experiences, which may have contributed to the depth and detail of the narratives collected.

A key strength of this study was the successful recruitment of participants within a relatively short timeframe of approximately three weeks, despite literature suggesting that South Asian populations are often difficult to recruit for research. Recruitment across multiple social media platforms enabled the study to reach a wide audience, and several participants also reported learning about the study through word of mouth. The researcher's shared cultural background and lived experience of endometriosis may have helped reduce feelings of shame or stigma associated with discussing the condition, which participants had previously identified as a barrier. In addition, offering flexible participation options, such as allowing cameras to remain off during interviews, helped create a more comfortable environment for participants who felt anxious about taking part. Many participants also expressed a desire to share their stories, highlighting the value of research approaches that create space for underrepresented voices to be heard. However, the brief recruitment period and reliance on social media recruitment may have reduced participation among individuals who are less active on social media or do not use such platforms, including certain age groups. While the sample reflected diversity in religion and geographical location, representation across age groups was more limited.

***Sample***

The sample included participants largely aged 20–38, which provided insight into the experiences of younger adults navigating endometriosis. Most participants had been diagnosed within the past six years, reflecting NHS care at a specific point in time. While this limits the generalisability of findings to older individuals whose experiences may differ, it is a strength in capturing how recent healthcare policies and practices impact lived experiences.

All participants in the current study spoke English fluently, as this was an inclusion criterion. While this facilitated detailed narrative interviews, it also excluded people who do not speak English well, potentially omitting the experiences of those from more marginalised linguistic and cultural backgrounds. Evidence from parliamentary inquiries into health inequalities suggests that language barriers can create additional obstacles to accessing care and disclosing health concerns, contributing to inequities in how conditions and symptoms are recognised and treated (Women and Equalities Committee, 2024). By focusing only on English-speaking participants, the study may therefore underrepresent the perspectives of individuals whose experiences are shaped by language exclusion, further marginalising these individuals.

Additionally, participants were not asked about the clinical stage or classification of their endometriosis. This may be considered a limitation, as the severity of the condition could influence individuals' physical symptoms, treatment pathways, and overall experiences, which were therefore not explored in relation to disease stage. A further limitation is that employment status, educational background, symptom duration, and time to diagnosis were not systematically or formally collected for all participants. These data were reported inconsistently and opportunistically during interviews, limiting the ability to provide a complete or comparable demographic and clinical profile across the sample. However, the absence of both clinical staging and standardised demographic/clinical variables may also be

viewed as a methodological strength, as the study prioritised participants' subjective narratives rather than biomedical categorisation, allowing experiences to be explored without framing them through clinical markers of severity.

### *Narrative Framework*

A key methodological strength of this study was the use of narrative analysis, which enabled participants' stories to be prioritised and understood within the broader context of their lived experiences. Narrative approaches are particularly suited to exploring complex and identity-related experiences, as they attend not only to the content of what is said but also to how individuals construct meaning through storytelling. This allowed the research to capture the temporal, emotional, and relational aspects of participants' experiences of living with endometriosis, rather than reducing accounts solely to discrete themes. However, despite the intention to privilege participants' voices, the process of analysing and presenting the findings inevitably involved interpreting and organising stories through the researcher's lens. As such, there remains a risk that the process of writing up the findings may fragment or reshape participants' narratives and foreground the aspects the researcher identified as most salient.

### *PPI*

Another strength of the study was the involvement of an expert by experience through PPI. Engaging individuals directly affected by the topic can help ensure that research is grounded in lived experience and supports the amplification of participant voices (Groot et al., 2020). This consultation also encouraged reflection on power dynamics within the research process and considerations around how participants' narratives were represented. However, due to limited funding, PPI input was restricted to three sessions. Greater involvement across all stages of the research process would have strengthened the study further and aligned more closely with working in a PCF framework. Reflections on the PPI process are discussed below.

**Future Research**

All participants in the current study identified as women using she/her pronouns. While this enabled exploration of the experiences of South Asian individuals who identify as women, it does not capture the perspectives of individuals living with endometriosis who do not identify as female. Emerging research suggests that transgender and non-binary individuals with endometriosis may face additional challenges, including gender dysphoria triggered by symptoms, misgendering in healthcare settings, and barriers to accessing affirming care (Eder & Roomaney, 2023, 2025). Therefore, the findings may not fully represent the diversity of experiences among all individuals living with endometriosis, highlighting the importance of including gender-diverse participants in future research.

As previously mentioned, participants were grouped under the broader category of South Asian; this population remains culturally and religiously diverse. Different communities and countries within South Asia have distinct historical, social, and political contexts, which may shape experiences in unique ways, including the impact of intergenerational trauma. Grouping these diverse backgrounds, therefore, risks overlooking important differences and nuances within participants' experiences. Future research would benefit from examining specific South Asian subgroups in greater depth to better capture the diversity and nuance within this population.

Additionally, as highlighted throughout the literature, endometriosis is a chronic condition that often begins during adolescence and currently has no cure. Future research would therefore benefit from including a broader age range of participants, capturing experiences from the onset of symptoms through to older adulthood. This would allow for a more comprehensive understanding of how individuals experience and navigate the condition across different stages of the lifespan.

Finally, there is a notable lack of research examining psychological interventions for individuals with endometriosis (Young et al., 2015), particularly for those from diverse cultural backgrounds. Future research should therefore explore the effectiveness of psychological interventions for endometriosis while also considering how such approaches can be adapted to be culturally competent and responsive to the needs of different communities.

**Reflections**

Within research writing, it is often suggested that anything discussed in the discussion should already have been introduced in the introduction. While I understand that this approach can help structure a study and allow topics to be explored in more detail, I often found myself questioning this expectation. I wondered why researchers are expected to have all the answers from the outset, when the very purpose of research is to learn and build understanding of a topic over time. Engaging with a critical and PCF-informed perspective encouraged me to reflect on this further, prompting questions about who established these conventions and for what purpose. It also highlighted the importance of learning through the voices and experiences of those who have not always been heard within research. Keeping this in mind, I made a conscious decision not to introduce every topic that later appeared in the discussion within the introduction. Instead, I wanted the thesis to reflect the process of learning that occurred throughout the research, and to acknowledge that it is acceptable within research not to have all the answers from the beginning.

Completing this research has had a profound impact on me. Listening to the experiences of individuals diagnosed with endometriosis was challenging at times, as I often recognised parts of their stories in my own experiences. At other moments, I found myself wondering whether I might encounter similar difficulties in the future. I often felt a deep sense of sadness for the participants as they described unanswered questions, missed opportunities, and the many struggles they endured to receive what should be basic healthcare. While I felt saddened

by these stories, I was not surprised by them. The difficulties faced by WAFAB within healthcare appear to reflect wider social issues. Despite many advances in areas such as technology and medicine, there remain aspects of society where women's health continues to be deprioritised, particularly for women from racialised backgrounds who may experience additional barriers and forms of discrimination.

I also noticed these patterns reflected in the research literature and in the process of writing this thesis. From early on, I found it challenging to hold together the three central aspects of this study: the gendered nature of endometriosis, the racialised experiences of South Asian women, and the condition itself as a chronic health issue. Much of the literature appeared to focus on only one of these areas at a time, rather than examining how they intersect. This sometimes made it difficult to structure the project in a way that felt cohesive, and I occasionally felt stuck when trying to create natural connections between these themes. Reflecting on this, I realised that this sense of "stuckness" in the writing process mirrored some of the experiences participants described when navigating healthcare systems and seeking a diagnosis.

Despite these challenges, I thoroughly enjoyed undertaking this research and writing the thesis. Interviewing participants brought the study to life, and their narratives were rich, thoughtful, and deeply meaningful. I felt privileged that they were willing to share such personal experiences with me, and their stories reinforced the importance of continuing research that centres the voices of those living with endometriosis.

Completing this research has reinforced for me the importance of listening to and valuing people's lived experiences within healthcare. I hope this research serves as a reminder to healthcare professionals across all fields that every person in front of them is more than a diagnosis or a set of symptoms. Each individual has their own dreams, aspirations, and hopes

for the future, and everyone deserves to be heard, believed, and treated with dignity. Ensuring equity in healthcare is essential so that all individuals, regardless of their background, have the opportunity to live well and pursue the futures they hope for.

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* *Indicates those included in the literature review in Chapter Two*.

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# Appendix

## Appendix A

Literature Review: Understanding the healthcare experiences of women with a diagnosis of endometriosis: a meta-ethnographic synthesis

### 1. Abstract

**Background:** Endometriosis is a chronic inflammatory disease of the uterus that can affect all areas of a woman's life: sex, social life, work, medical experiences, symptoms, and infertility. It has been suggested that women often face a difficult journey in acquiring a diagnosis and receiving treatment for symptoms.

**Methods:** This meta-ethnography included eight qualitative studies to examine women with endometriosis' experiences of accessing physical healthcare services globally.

**Results:** The synthesis revealed a unique understanding of women's experiences which can be conceptualised on four different levels: barriers to care, shortcomings in health care systems, living with endometriosis, and self-care. The findings illustrate the multiple difficulties women face and the impact of the limited support to address this.

**Conclusion:** This synthesis revealed the need for change within healthcare encounters, such as increased access to professionals and better training. More research exploring experiences of using the UK health system is needed to better understand how needs can be addressed.

## 2. Introduction

The concept of "women's health" has received more attention globally in recent years in terms of legislation, policy, and practice (e.g. Berger et al., 2019; Department of Health and Social Care [DHSC], 2022; The Royal College of Obstetricians and Gynaecologists, 2019). It has been reported that gender biases exist within healthcare systems across the world, with the UK having the largest health gap out of the twenty largest economies in the world and the twelfth largest globally (Manual, 2021). Several reports and inquiries have highlighted situations where women have suffered harm due to poor healthcare (Chen et al., 2008; DHSC, 2020a; DHSC., 2020b) with one of the most recent and prominent examples being the "maternity scandal", which revealed instances of patient mortality could have been avoided had women been listened to and the right healthcare been received (Knight et al., 2014).

Proposed explanations of healthcare disparity come from feminist scholars who suggested that our understanding of gender-related conditions in women is restricted by the predominantly male viewpoint, which has historically shaped medical research and practice (Seear, 2016; Sen & Östlin, 2008; Ussher, 2006).

The publication of inquiries and media coverage of incidents has led to increased awareness of the difficulties faced by women in healthcare settings, which is being reflected in policy and practice. For example, The National Health Service (NHS) long-term plan highlighted the need for enhanced care in maternity services (NHS, 2019). Additionally, in 2021 the DHSC launched a call for evidence to inform the first-ever government-led Women's Health Strategy for England. Respondents reported that gynaecological conditions are the top area women wanted DHSC to focus on and highlighted that they felt better research was needed into health issues specific to women, such as endometriosis and menopause (DHSC, 2021).

Endometriosis is an inflammatory disease in which tissue similar to the lining of the uterus grows outside the uterus (Johnson et al., 2017). This leads to inflammation and scar tissue forming in the pelvic region and sometimes elsewhere in the body (Burney & Giudice, 2012). It is said to affect 5-10% of women of reproductive age globally and symptoms include but are not limited to dysmenorrhea, dyspareunia, chronic pelvic pain, bleeding, fatigue, and, in some cases, urological or gastrointestinal symptoms (such as dysuria, dyschezia) (Smolarz et al., 2021; Saunders & Horne, 2021; Pettersson & Bertero, 2020). Endometriosis can also cause

compromised fertility or infertility, and research suggests that 50% of women seeking help for infertility had endometriosis lesions (Saunders & Horne, 2021).

Diagnosis of endometriosis typically relies on laparoscopy, the primary method for confirmation, often supported by histology (Saunders & Horne, 2021). On average, women wait between 4-10 years for a diagnosis (Pugsley & Ballard, 2007; Taylor et al., 2021). Several factors contribute to delayed diagnosis, including misdiagnosis and overlooking symptom severity (Taylor et al., 2021). This is despite clinical guidelines stating that individuals should be referred to specialist services and further investigated even if tests (e.g. abdominal or pelvic examination, ultrasound, MRI) come back normal, but symptoms persist (National Institute of Health and Care Excellence [NICE], 2017). Delays are frequently linked to the necessity of laparoscopy and histology. However, this can impact reproductive potential and overall functional outcomes (Saunders & Horne, 2021; Taylor et al., 2021).

A systematic review looking into women's experiences of endometriosis (Young et al., 2015) found that it affected all areas of life; sex, social life, work, medical experiences, symptoms, and infertility. It also highlighted the lack of research focusing on women's encounters with infertility linked to endometriosis and the effects of diminished social engagement on their perceived support and emotional well-being. Additionally, it indicated a notable absence of systematic reviews or meta-analyses addressing psychological support for women dealing with endometriosis or exploring their encounters within healthcare settings.

Pettersson and Bertero (2020) carried out a systematic review looking into "how women experience healthcare encounters", with the aim of interpreting the available qualitative studies to increase our understanding and extend knowledge on the topic (Pettersson & Berterö, 2020). The review found that professionals had insufficient knowledge, did not take women's concerns seriously, and that healthcare professionals'(HCPs) willingness to help, learn, and listen impacted women's experiences and journey to diagnosis.

Ecological Systems Theory (EST) (Bronfenbrenner, 1977) places the individual at the centre, highlighting dynamic interactions between different systems and how they collectively influence over time. The microsystem is the immediate environment that directly impacts the individual (e.g., family, friends, work, GP). The mesosystem identifies interactions between the microsystem, such as those between family and work. The exosystem is comprised of external settings that indirectly impact an individual (e.g., partners' work, community resources) and the macrosystem represents broader cultural contexts and societal values. The

chronosystem is the dimension of time, which considers changes and transitions in a person's life and the broader socio-historical context. EST therefore suggests that difficulties in healthcare settings can influence other areas of our lives, which helps explain why studies have found WWE face multiple difficulties (e.g. Young et al., 2015). This also emphasises the significance of meeting health needs for psychological safety and overall quality of life (QOL).

Over the last 5 years, there has been an increase in the awareness of the difficulties women face in healthcare settings and increased awareness of endometriosis as a chronic illness, partially due to information being shared on social media (Metzler et al., 2022; Towne et al., 2021). Therefore, this systematic review aims to update the current literature and further explore (and subsequently understand) how women with endometriosis (WWE) experience healthcare encounters and how policy and practice might seek to best support these individuals.

The exploration will involve synthesising contemporary research to offer an updated review of the rapidly evolving area of health provision. In order to review the current research surrounding endometriosis when it comes to accessing a range of physical healthcare services globally (such as GPs and specialised gynaecology clinics) the following research question was formulated: *How do WWE experience healthcare encounters?* This study aims to enhance the understanding of the experiences of WWE and influence service provision. For this study, "women" are defined as those assigned female at birth, which does not necessarily represent gender identity.

## 3. Methods

### 3.1. Design

While traditional meta-analyses primarily handled quantitative data, recent approaches have emerged for synthesising qualitative research (Atkins et al., 2008; Campbell et al., 2003; Pound et al., 2005). Noblit and Hare's (1988) meta-ethnographic approach provides an interpretative framework for qualitative data, using a seven-phase process to organise and synthesise data from multiple studies, capturing diverse perspectives (Priestly & McPherson, 2016). Systematic comparisons of key concepts help determine the comparability, contradictions, or representation of specific arguments across studies (Priestley & McPherson, 2016). Meta-ethnographies have proven value in analysing healthcare experiences and more specifically chronic illness (Britten et al., 2002; Atkins et al., 2008). Its strength lies in offering an

interpretative framework across studies while preserving the richness of collected data (Atkins et al., 2008). Therefore, the meta-ethnographic approach was considered suitable for maintaining the depth of information regarding the lived experiences of WWE. The current meta-ethnography adhered to Noblit and Hare's (1988) seven-phase process: getting started; deciding what is relevant to the initial interest; reading the studies; determining how the studies are related; translating the studies into one another; synthesising translations; expressing the synthesis

### 3.2.Article Selection

To define topics of interests and guide search strategy the SPIDER framework (Cooke et al., 2012) was followed (Table 1). All published, peer-reviewed articles that used qualitative methods to explore the experiences of women with a diagnosis of endometriosis experience of healthcare encounters were included. Qualitative methods were defined as face-to-face interviews, focus groups, or questionnaires with free-text responses followed by a form of in-depth analysis. To ensure the greatest clarity of WWE experiences, articles were excluded if participants with other diagnoses such as polycystic ovaries or adenomyosis were also included and the data were merged. Additionally, articles were only included if the diagnosis had been confirmed by a medical professional (e.g. via laparoscopy or scans). Articles were excluded if the interviews were not from WWE's point of view. However, articles were included if women’s and another group's views were included and analysis was conducted and reported separately. Studies with irrelevant research focus were excluded (such as pain, and implementing GP systems). Articles focussing on the experience of accessing psychological services were also excluded as the focus of the current meta-ethnography is on physical healthcare services (rather than psychological care which would warrant a separate study). Mixed methods articles were included if qualitative data analysis was reported separately.

**Table 1.**

*SPIDER criteria for study eligibility and inclusion*

| Criteria | Definition |
|---|---|
| Sample | Women with a diagnosis of endometriosis |
| Phenomenon of interest | Experiences of healthcare services |
| Design | Interviews, focus groups |
| Evaluation | Views, experiences |
| Research type | Qualitative |

An electronic search was conducted using databases CINAHL Ultimate, APA PsycINFO, APA Psycharticles, MEDLINE Ultimate, and SCOPUS in December 2023. Due to a large number of results, the search criteria were refined using the limiters 'journal article', 'English language" and 'Title and Abstract'. It was also decided to use a '2019-2023' date range to remove articles preceding 2019 that were included in the meta-synthesis carried out by Pettersson and Bertero (2020) as the aim of this study is to update the literature and compare findings. The search terms employed are seen in Table 2.

**Table 2.**

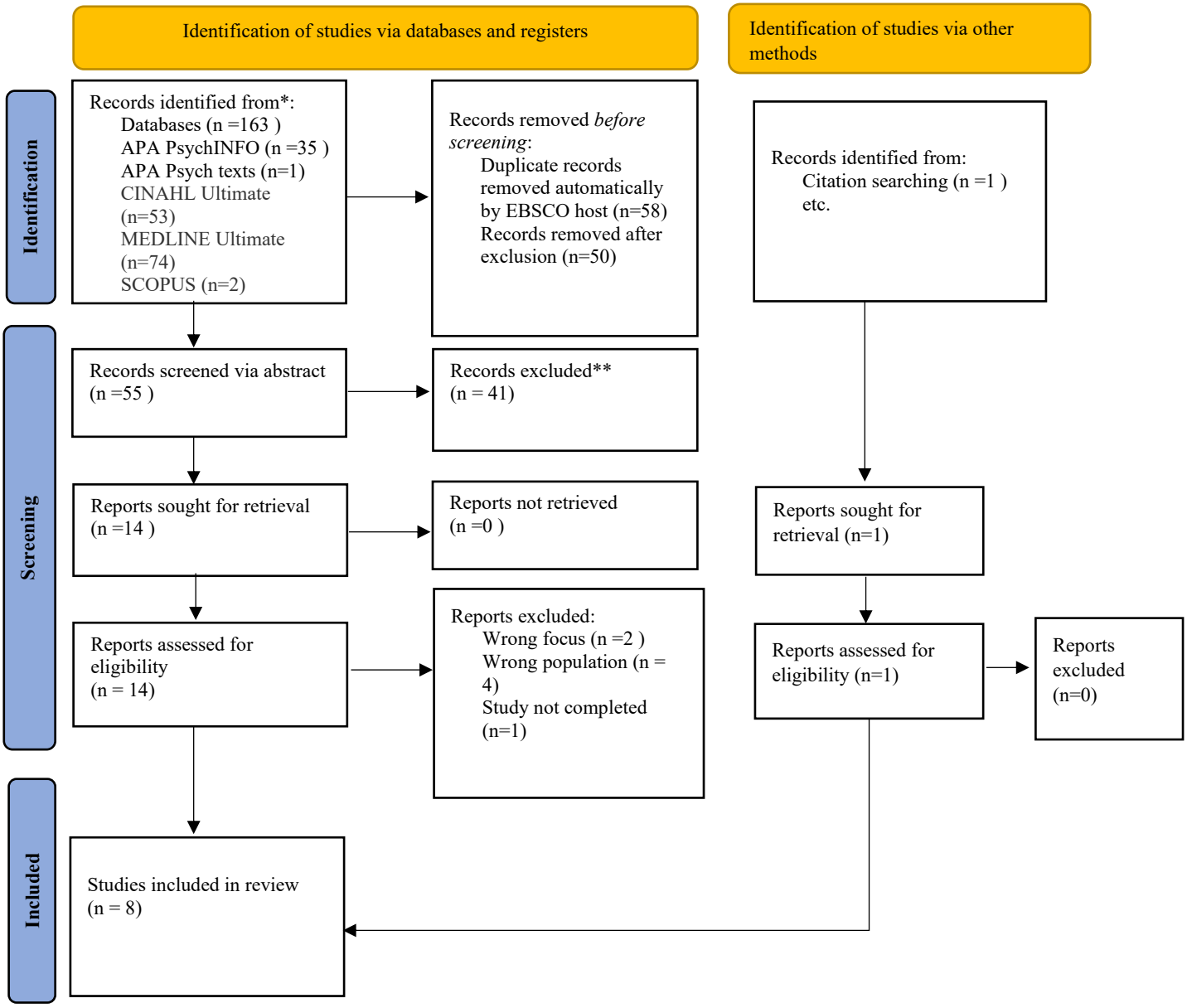
*Search terms used to retrieve articles*

| Search Number | Search Term |
|---|---|
| 1 | wom?n or female |
| 2 | endometriosis or endometrioses or endometrioma or endometriomas |
| 3 | healthcare or GP or "general practitioner" or physician* or "primary care" or practitioner* or doctor* or "health professional" or "medical professional" |
| 4 | Experience or Perspective or View or Perception or Attitude or Opinion or Interpretation |
| 5 | qualitative OR ethnograph* OR phenomenol* OR ethnonurs* OR grounded theor* OR lived experience* OR narrative* OR life experiences OR thematic analysis OR theoretical sample OR discourse analysis OR focus group* OR ethnological research OR ethnomethodolog* OR interview* |
| 6 | S1 AND S2 AND S3 AND S4 AND S5 |
| 7 | Limiters: English language and 2019-2023 and peer reviewed journal |

The journal titles and abstracts were then scanned in detail; seven were selected for inclusion (Bergen et al., 2023; Márki et al., 2022; Mikesell & Bontempo, 2023; Rowe et al., 2021; van der Zanden et al., 2021; Young et al., 2020; Zale et al., 2020). The reference lists of the selected journals were then searched to identify further relevant literature. This yielded one further study (Evans et al., 2022).

**Figure 1.**

*PRISMA flow diagram showing the search process (Page et al., 2021).*



### 3.3. Determining how the studies are related

Eight studies underwent examination to uncover recurring and shared concepts. These emerging concepts were being heard and believed, HCP knowledge and skills, treatment options, multidisciplinary care, medical experience, self-advocacy, coping strategies, QOL, and Stigma. Appendix 1 demonstrates the organisation of data from one study, with each study in columns and the primary concepts in rows. The initial four rows detail relevant aspects of the study setting and design, crucial contextual information for the synthesis. Subsequent rows correspond to key concepts identified. The final row pertains to the central theory or interpretation derived from each study, referred to as second-order interpretations (Britten et al., 2002).

### 3.4.Translating the studies into one another

After compiling the summary tables for individual studies the analysis focused on identifying key themes across all papers. Some suggest that reading papers sequentially might impact the themes found in later papers (Atkins et al., 2008). We aimed to minimise this by staying open to new emerging themes throughout the process. Themes were combined into a comprehensive table (Table 3) that compared studies based on their shared concepts.

**Table 3.**

*Cross-comparison of studies by concept*

| **Concepts** | Zale et al., (2020) | Young et al., (2020) | van der Zanden et al., (2021) | Rowe et al., (2021) | Marki et al., (2022) | Evans et al., (2022) | Bergen et al., (2023) | Mikesell & Bontempo et al., (2023) |
|---|---|---|---|---|---|---|---|---|
| Being heard and believed | | * | * | * | | | * | * |
| HCP knowledge and skills | | * | * | * | | | * | * |
| Treatment options | * | | | * | * | * | | |
| Multi-disciplinary care | | | * | * | | | | |
| Medical experiences | * | | | * | * | * | | * |
| Self-Advocacy | * | * | | | | * | * | * |
| Coping strategies | | | | * | * | * | * | |

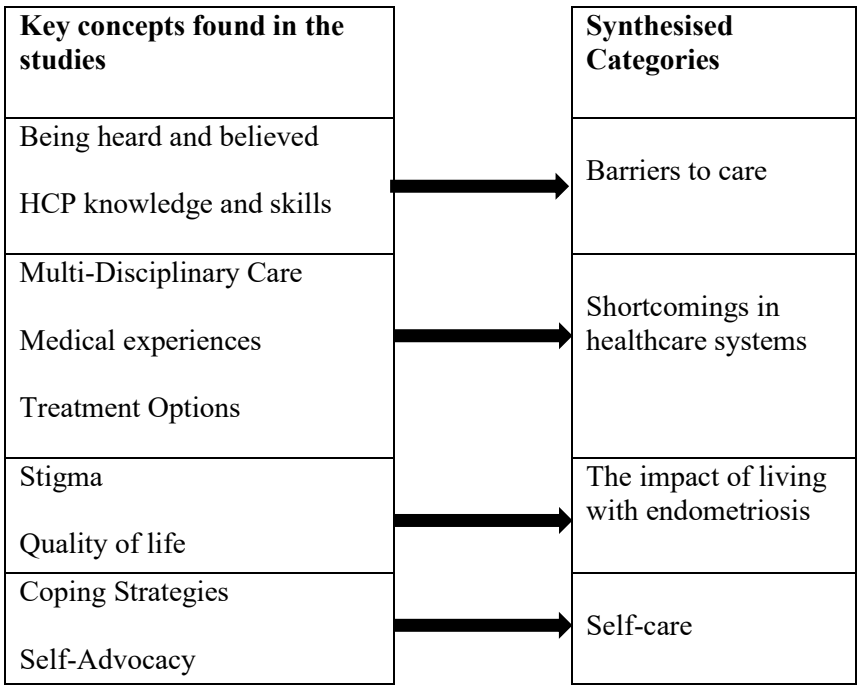
| | | | | | | |
|---|---|---|---|---|---|---|
| Quality of life | * | | * | * | | * |
| Stigma | | | * | | * | * |

### 3.5. Synthesising the translation

While replicating the synthesis process exactly is challenging, this meta-ethnography adhered to the approach outlined by Atkins et al. (2008). Tables from each paper were analysed side by side, conducting a thorough cross-comparison of concepts and second-order interpretations. The emerging concepts took shape in the form of a reciprocal translation; the studies were about similar things (Britten et al., 2002, Noblit and Hare, 1988). Four categories were developed at this stage: Barriers to care, shortcomings in healthcare systems, the impact of living with endometriosis, and self-care. These were subsequently analysed and developed into a line-of-argument synthesis, where key categories and second-order interpretations were developed (Figure 2).

**Figure 2.**

*Summary of key concepts and synthesised categories.*



# 4. Results

## 4.1. Quality assessment

Authors who have conducted meta-ethnographies have differing opinions on how to apply quality assessment. Some choose to exclude low-quality studies (Fosse et al., 2014), while others refrain from excluding any studies and, instead, utilise the quality assessment data to determine each study's contribution to the synthesis (Atkins et al., 2008). The current meta-ethnography used an adapted version of the CASP (Critical Appraisal Skills Programme UK, 2018), however, all articles were included, regardless of quality. This approach mirrored Atkins et al.'s (2008) choice to include all journals that fulfilled their predetermined basic criteria with the assumption that peer-reviewed journals maintain a good level of quality.

The results of the CASP analysis suggested varying quality across the studies. Seven out of eight studies provided clear research aims, whilst one failed to clearly outline its aims (Mikesell & Bontempo, 2023). Atkins et al., (2008) suggest that having a clear research aim is the most important step in carrying out research; the absence of this could contribute to the overall lower quality of research compared to other studies in the synthesis. While some studies adequately detailed sample selection and research design, others lacked clarity in explaining the methods employed for qualitative analysis. (Rowe et al., 2021; Bergen et al., 2023). One study displayed excessive synthesis, resulting in a diminished richness in the original data (Mikesell & Bontempo, 2023) leaving the studies integrity at question (Campbell et al., 2011).

Ethical approval was sought in six papers, however, one paper made no reference to ethical approval (Mikesell & Bontempo, 2023). Zale et al., (2020) remarked they were exempt from applying, but did not explain this. Despite the majority of studies referring to the process of ethical approval, only one study provided further detail about the consideration of ethical issues during the recruitment and interview process, how this was managed and the implications for the research (Young et al., 2020). One study had a particularly small sample size ($n<20$) (Zale et al., 2020), which was acknowledged by the authors who stated findings may not be representative of the wider population.

The studies were carried out in Australia, the United States, Kenya, the Netherlands, and Hungary, reflecting a wide range of cultures and healthcare systems. Nevertheless, most of the

study samples were considered homogenous in age, education level, marriage status, and sexual identity. Two studies failed to report a range of demographic information about participants (Evans et al., 2022; van der Zanden et al., 2021).

**Table 4.**

*Table showing key features of the study*

| Author | Location | Participants | Study aim | Methodology | CASP score |
|---|---|---|---|---|---|
| Zale et al., (2020) | United States | n=12 | Experience of being a WWE in the USA | Semi-structured interviews | 15 |
| Young et al., (2020) | Australia | n= 26 | Experience of navigating knowledge and power for WWE | Semi-structured interviews | 17 |
| van der Zanden et al., (2021) | Netherlands | n=23 | Experience of the diagnostic process for WWE | Focus groups | 16 |
| Rowe et al., (2021) | Australia | n=46 | Experience of healthcare encounters from WWE and healthcare providers' point of view | Online discussion groups | 14 |
| Evans et al. (2022) | Australia | n=532 | Experience of treatment satisfaction for WWE | Open-ended questionnaires | 15 |
| Marki et al., (2022) | Hungary | n=21 | Experience of the difficulties living as a WWE | Focus groups | 17 |
| Mikesell & Bontempo et al., (2023) | United States | n=997 | Experience of health care professionals by WWE | Open-ended questionnaires | 11 |
| Bergen et al., (2023) | Kenya | n=37 | Experience of living with endometriosis as a WWE in Kenya | Online questionnaires | 15 |

*Note: CASP scoring Yes=2, Can't tell =1, No =0*

### 4.2. Barriers to care

#### *4.2.1. Being heard and believed*

Seven out of the eight studies included in this synthesis reported themes relating to being dismissed. Women spoke of doctors normalising their symptoms and dismissing concerns, which often fractured the patient-carer relationship. There was a general sense of frustration at

the lack of empathy and respect HCPs showed towards WWE, which often left women feeling patronised (Bergen et al., 2023; Evans et al., 2022; Mikesell & Bontempo, 2023; Rowe et al., 2021; van der Zanden et al., 2021; Young et al., 2020; Zale et al., 2020). This was a key frustration, which some felt contributed to the delay in diagnosis. Even after receiving a formal diagnosis, some women spoke of how they still felt their concerns relating to symptoms were dismissed. WWE spoke of wanting to be treated with compassion, and to have their embodied experiences acknowledged and their symptoms taken seriously. They recognised the power that doctors held as facilitators to care. Only one study spoke of positive experiences with HCPs (Mikesell & Bontempo, 2023) but noted the impact of positive experiences was so influential they counterbalanced the negative experiences, with participants describing them as "life-changing".

#### *4.2.2. HCP knowledge and skills*

There was a consensus amongst women that HCPs lack knowledge and skills related to women's health and more specifically endometriosis (Bergen et al., 2023; Evans et al., 2022; Mikesell & Bontempo, 2023; Rowe et al., 2021; van der Zanden et al., 2021; Young et al., 2020; Zale et al., 2020). Some women reported that HCPs would repeatedly take the same approach rather than suggest different ways of moving forward, which exemplified their lack of knowledge. Others stated that they do not expect doctors to know everything, but they should be honest about what they do not know (Young et al., 2020). Women reported being given the wrong treatments or being referred to inappropriate pathways due to the lack of knowledge by HCPs. It was also reported by some that gynaecological conditions were not initially considered. Many women saw multiple professionals throughout their journey to diagnosis which one described as "doctor shopping" until they found someone who was able to help (Marki et al., 2022).

### 4.3. Shortcomings in healthcare systems

#### *4.3.1. Multidisciplinary care*

The concept of multidisciplinary care was perceived as absent in WWE experiences (Rowe et al., 2021; van der Zanden et al., 2021). These women expressed the need to consult multiple HCPs to address the diverse symptoms and intricate nature of their condition. However, they noted a sense of disjointed care, characterised by prolonged waits for referrals to different

professionals. Women believed that a broader range of HCPs should have been accessible, advocating for a more holistic approach to enhance the overall effectiveness of their care.

#### *4.3.2. Medical experiences*

Women shared various predominantly negative medical encounters (Evans et al., 2022; Márki et al., 2022; Mikesell & Bontempo, 2023; Rowe et al., 2021; Zale et al., 2020). These experiences encompassed diagnostic delays attributed to HCPs' lack of knowledge or initial misdiagnosis. Accessibility was also highlighted as contributing to negative experiences (Bergen et al., 2023; Evans et al., 2022; Rowe et al., 2022) with some encountering challenges in accessing affordable healthcare (Bergen et al., 2023), while others faced geographical barriers, with necessary care unavailable in rural areas (Bergen et al., 2023; Evans et al., 2022). Instances of inadequate and inconsistent information, along with dissatisfaction with medical professionals, were also contributing factors.

#### *4.3.3. Treatment options*

In studies addressing treatment options (Márki et al., 2022; Rowe et al., 2021; Zale et al., 2020; Evans et al., 2022), women expressed frustration with the limited treatment choices at their disposal despite the high prevalence of the disease (surgery or hormone therapies). They were dissatisfied with the reliance on hormone therapy which left them feeling constrained in managing symptoms, with concerns about potential adverse effects of surgical procedures. Additionally, they reported that care plans were typically short-term, lacking consideration or explanation of long-term implications.

### 4.4. The impact of living with endometriosis

#### *4.4.1. Stigma*

Stigma was a factor linked with difficulties experienced in health encounters, as well as among other relationships (Bergen et al., 2023; Evans et al., 2022; Rowe et al., 2021). One study reported that the stigmatisation was amplified by the attitudes of HCP and labels such as “attention seeking” (Bergen et al., 2023). Contrastingly, Evans et al., (2022) stated that it was not clear who was responsible for the stigmatisation of the disease and associated symptoms. Stigmatisation left women with a sense of shame over the difficulties they faced relating to endometriosis which made the experience of healthcare encounters more difficult.

#### *4.4.2. Quality of life*

QOL was shaped by the impact of the disease on the lives of WWE outside healthcare settings. Women highlighted its pervasive influence on various areas, including work, mental health, and relationships (Zale et al., 2020; Bergen et al., 2023; Marki et al., 2022; Rowe et al., 2021). There was particular emphasis on the psychological impact, with reported inadequate support. Women also mentioned that symptoms, such as enduring chronic pain, significantly hindered their ability to participate in activities that could improve their QOL.

### 4.5. Self-Care

#### *4.5.1. Coping Strategies*

Varying coping strategies were reported in studies. Rowe et al., (2021) reported women engaging in "self-help" activities such as relaxation and meditation. Whilst Marki et al., (2022) reported women engaging in lifestyle changes including dietary changes and "remaining positive". Other coping strategies included self-efficacy, building a good support network, and building resilience. Women spoke of having to find their own ways to manage, due to the lack of knowledge and support they received from HCP.

#### *4.5.2. Self- Advocacy*

The studies highlighted that WWE often had to research and advocate for themselves. Women spoke about being their own advocates as HCPs were unable to advocate for them. Women felt self-advocacy was often what led to success in moving forward in their diagnosis and treatment journey (Zale et al., 2020; Evans et al., 2022; Mikesell et al., 2023; Young et al., 2019; Bergen et al., 2023). They noted that their internal strength, knowledge, and power were just as important as learning to live with the disease.

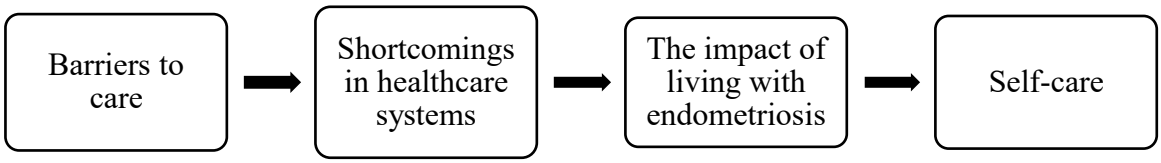
### 4.6. Line of argument synthesis

The process of line-of-argument synthesis, as outlined by Noblit and Hare (1988), involves constructing a new third-order conceptual understanding. The synthesis revealed a process comprising four phases that WWE undergoes during their healthcare experiences for endometriosis. WWE initially experience barriers to care, which often starts at the onset of symptoms but can last many years as symptoms persist and increase over time. They are then affected by the shortcomings in healthcare systems which can be inaccessible and reveal a lack

of multi-disciplinary care and treatment options. Their journeys of living with endometriosis involve shame and stigma, and over time, their QOL decreases as symptoms persist. This can affect all areas of their lives including work/school, family/friendships, and socialising, demonstrating a negative impact. Due to the difficulties and challenges they face, WWE have to participate in self-care, advocating and educating themselves on their health, and participating in coping strategies that allow them to move forward.

**Figure 3.**

*Line of argument synthesis: different levels of WWE experience of healthcare*




## 5. Discussion

Through translation, this meta-ethnographic synthesis of eight studies shows that there is a pattern of key concepts that are common for WWE in their healthcare experiences globally: barriers to care, shortcomings in healthcare systems, the impact of living with endometriosis, and self-care. The line-of-argument synthesis revealed a process that WWE undergo whilst attempting to receive a diagnosis and treatment for the disease. Together, the key concepts and line-of-argument synthesis reveal that there are multiple difficulties faced with little support available to address them.

Pettersson and Bertero (2020) conducted a meta-synthesis of the literature between 2000 and 2018. There are some similarities between the results of their analysis and the current study. They reported three fusions: insufficient knowledge, trivializing—just a women's issue, and competence promotes health. Whilst the key concepts are not identical, they incorporate similar ideas. For example, this study reports "barriers to care" as a synthesised concept that includes HCPs limited knowledge and skills as one of the main barriers to care. Pettersson and Bertero (2020) reported "insufficient knowledge" as a fusion from their synthesis and spoke about HCPs' lack of knowledge in the area which led to the normalisation of symptoms, incorrect diagnoses, and treatment based on medical myths.

Pettersson and Bertero (2020) fusion of “trivialising” speaks of how endometriosis was generally seen as “just a woman's problem” and therefore the onus was put back on women to find their own solutions, as treatment options were not available or were limited. This combines ideas from the concept of “treatment options” and “self-care” in the current study.

Pettersson and Bertero’s (2020) final concept “competence promotes help” focuses on the positive encounters women had with HCP and how these led to better health outcomes. The lack of positive experiences reported in studies in the current synthesis may be due to the small number of papers included.

Overall, the synthesis from Pettersson and Bertero (2020) reveals similar results to the current study; that women are treated with disrespect and have a difficult journey with diagnosis and treatment. This study, like others, highlighted that the difficulties within healthcare experiences have a much wider effect on WWE lives. As aforementioned, this can be explained by EST which suggests that healthcare sits within individuals' microsystems but interacts dynamically with all other systems. For instance, inadequate healthcare may heighten symptom severity, resulting in more work absences. This can lead to reduced income (as endometriosis lacks government financial support). The financial strain may limit participation in social activities, ultimately affecting relationships and demonstrating the impact across all systems.

These results might imply that, despite increased awareness of gender-related issues, the experiences of women have not changed significantly in recent years. Alternatively, this could represent the disruption in fields of health and research, which were notably affected by the coronavirus pandemic which accounts for part of the period covered in the current study.

There are several ways in which legislation, policy, and practice could support WWE. With HCPs being seen as lacking insufficient knowledge and skills, the General Medical Council (the regulatory body for doctors in the UK) could suggest mandatory training in the field of women’s health, including endometriosis, to increase the competency of doctors in this area. NICE guidelines already suggest that a holistic approach to care should be taken, where women have access to different HCPs to help manage symptoms and ensure an efficient process of diagnosis and treatment (NICE, 2017). Services across the country must follow this legislation to ensure the best clinical care. NICE should include service users in the consultation for future guidance, to create a shared understanding of experience and needs between healthcare providers and patients (NHS England, 2022). The current legislation lacks recommendations

for psychological care for patients with endometriosis, despite WWE highlighting that the disease impacted their lives significantly. This must be included in future guidance.

Although the government expresses a commitment to women's health (DHSC, 2022), the capacity for change may be constrained by the existing economic conditions. EST explains this within the macrosystem, which encompasses economic structure. The NHS faces challenges like underfunding, lengthy waitlists, and staff shortages (Anderson et al., 2021). To identify necessary changes and the required funding for WWE using the UK healthcare system, research specific to this group is crucial. Future research should look at WWE experiences in the UK, making sure to recruit a heterogeneous sample.

### 5.2. Limitations

No study in the current meta-ethnography involved participants residing in the UK, primarily due to the limited research in this specific area. Consequently, this restricts the synthesis's breadth. Diverse healthcare systems across various countries and regions mean experiences cannot be universally applied and results cannot be generalised. This underlines the need for additional research specifically addressing the experiences of WWE in the United Kingdom. Such insights could significantly contribute to informing policies and practices to help address the issues highlighted by women globally.

A further limitation is the inclusion of studies that used online questionnaires. It has been suggested by some researchers (e.g. O'Cathain & Thomas, 2004) that questionnaires do not allow for the same depth and quality of response as focus groups and in-person interviews. This again highlights the need for further research into endometriosis so that a wider variety of research is available to synthesise.

Additionally, meta-syntheses typically involve a team of researchers. In this study, a single reviewer conducted the synthesis, which might lead to biased results and interpretations skewed toward the researcher's perspectives.

## 6. Conclusion

All eight papers contribute significantly to the qualitative literature on WWE's experience of healthcare encounters and highlight the difficulties that are often faced. This meta-ethnography elicits a new model of the different levels of experience: barriers to care, shortcomings in

healthcare systems, the impact of living with endometriosis, and self-care. More research exploring WWE's experiences of using the United Kingdom health system is needed to better understand how their needs can be addressed so that their voices can help influence policy and practice.

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# 8. Appendix

## Appendix 1

*Sample of tabulated study details and key concepts.*

| **Methods and concepts** | **Young et al., (2020)** |
|---|---|
| **Key study details** | |
| Purpose | To describe how WWE navigate knowledge and power within the medical encounter |
| Setting | Australia |
| Sample | 26 women |
| Data collection | Telephone interviews |
| **Key concepts** | |
| Women's perceptions of doctors' knowledge and power | Medical professionals have a lack of knowledge and expertise in the area of endometriosis, there is a power imbalance between patient and doctor |
| Women's perceptions of their own knowledge and power | Women know their bodies. They have to advocate for themselves and be their own doctor. |
| What women want: To be heard and believed | Women are dismissed by doctors but want their doctors to believe them and treat them with respect |
| **Explanation/theory (Second-order interpretation)** | Medical education needs to equip doctors with the skills to acknowledge and incorporate women's knowledge of their bodies and understand how their practice affects women's social and economic participation. |

# Appendix B

Table with CASP scores for reviewed papers

| Author and Publication Year | 1. Aims | 2. Qualitative Methodology | 3. Research Design | 4. Recruitment | 5. Data Collection | 6. Relationship | 7. Ethical Issues | 8. Data Analysis | 9. Findings | 10. Value | Total Score |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Ballard, Lowton & Wright (2006) | 1 | 1 | 1 | 0.5 | 1 | 1 | 0.5 | 0.5 | 1 | 1 | 8.5 |
| Clark (2012) | 1 | 1 | 1 | 0.5 | 1 | 1 | 1 | 1 | 1 | 1 | 9.5 |
| de C Williams et al., (2025) | 0.5 | 1 | 0.5 | 0.5 | 1 | 1 | 0.5 | 1 | 1 | 1 | 8 |
| Denny & Mann (2007) | 1 | 1 | 1 | 1 | 1 | 0 | 0.5 | 0.5 | 1 | 1 | 8 |
| Denny & Mann (2008) | 0.5 | 1 | 1 | 1 | 1 | 0 | 0.5 | 0.5 | 1 | 1 | 7.5 |
| Denny (2004) | 1 | 1 | 1 | 1 | 1 | 0 | 0.5 | 0.5 | 1 | 1 | 8 |
| Denny (2009) | 1 | 1 | 1 | 1 | 1 | 1 | 0.5 | 1 | 1 | 1 | 9.5 |
| Drabble et al., (2021) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 |
| Grogan, Turley & Cole (2018) | 1 | 1 | 1 | 1 | 1 | 1 | 0.5 | 0.5 | 1 | 1 | 9 |
| Grogan, Turley & Cole (2021) | 1 | 1 | 1 | 1 | 1 | 0 | 0.5 | 0.5 | 1 | 1 | 8 |
| Harpur (2023) | 1 | 1 | 1 | 1 | 1 | 0.5 | 1 | 1 | 1 | 1 | 9.5 |
| Jones, Jenkins & Kennedy (2004) | 1 | 1 | 1 | 1 | 1 | 0 | 0.5 | 1 | 1 | 1 | 8.5 |
| Karavadra et al., (2025) | 1 | 1 | 1 | 1 | 1 | 1 | 0.5 | 1 | 1 | 1 | 9.5 |
| Law et al., (2025) | 1 | 1 | 0.5 | 0.5 | 1 | 0.5 | 0.5 | 0.5 | 1 | 1 | 7.5 |
| Taylor (2024) | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 10 |
| Varney (2022) | 1 | 1 | 1 | 1 | 1 | 0 | 0.5 | 1 | 1 | 1 | 8.5 |
| Wren & Mercer (2022) | 1 | 1 | 1 | 1 | 1 | 1 | 0.5 | 0.5 | 1 | 1 | 9 |

*Note: 1 indicates the criterion was met; 0.5 indicates the criterion was partially met or the required information was unclear or insufficient; 0 indicates the criterion was not met. CASP items: 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between the researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research?*

# Appendix C

Table showing participant ethnicities from included studies

| Author | Participants Ethnicities |
|---|---|
| Ballard, Lowton & Wright (2006) | Not reported |
| Clark (2012) | 13 White British |
| Denny & Mann (2007) | 27 White British,<br>1 Afro-Caribbean British,<br>1 Indo-Caribbean,<br>1 South American Indian |
| Denny & Mann (2008) | 27 White British,<br>1 Afro-Caribbean British,<br>1 Indo-Caribbean,<br>1 South American Indian |
| Denny (2004) | Not reported |
| Denny (2009) | 27 White British,<br>1 Afro-Caribbean British,<br>1 Indo-Caribbean,<br>1 South American Indian |
| Drabble et al., (2021) | 16 White British,<br>2 White European,<br>1 Black African,<br>1 Missing Data |
| Grogan, Turley & Cole (2018) | 30 White,<br>1 White & Black Caribbean,<br>1 Persian,<br>1 Asian,<br>1 Black British |
| Grogan, Turley & Cole (2021) | 30 White,<br>1 White & Black Caribbean,<br>1 Persian,<br>1 Asian,<br>1 Black British |
| Harpur (2023) | Not reported |
| Jones, Jenkins & Kennedy (2004) | Not reported |
| Karavadra et al., (2025) | 11 White British,<br>1 Asian Indian,<br>1 Black African,<br>1 Asian British,<br>1 Asian Mixed |

| | |
|---|---|
| Law et al., (2025) | 14 White British,<br>6 South Asian,<br>1 Mixed White & Asian,<br>1 White Other |
| Taylor (2024) | 8 Black |
| Varney (2022) | 9 White British,<br>3 Any Other White Background,<br>1 Asian,<br>1 Black |
| Williams et al., (2025) | 9 White,<br>4 Black,<br>3 Asian |
| Wren & Mercer (2022) | Not reported |

# Appendix D

PPI Contract

Contract between [redacted] and Miss Johal-Ayub

Dear [redacted]

Thank you for agreeing to provide 'How women of South Asian Heritage experience the journey to a diagnosis of endometriosis: Consultation' sessions with myself, Miss Johal-Ayub, for the duration of my doctoral thesis. This is a written contract to make our agreements final and clear-cut.

Actions on behalf of Miss Johal-Ayub:

- Utilise 3x 60-minute consultation sessions with Mrs Heera-Shergill, Founder of Cysters
- To provide payment of £30 per session in vouchers, which will total £90 once all sessions have been attended.

Actions on the behalf of Mrs Heera-Shergill:
Provide 3x 60-minute consultation sessions to Miss Johal-Ayub, which will aim to fulfil the following:

- Help shape the topic guide/questions in the interview schedule and theme checking ensuring the topics hold resonance for the participants
- Provide feedback on the recruitment methods
- Provide recommendations for relevant literature (if possible)
- Help the researchers think about language in different aspects of the study (e.g., recruitment poster/key terms/interview questions/title)
- Provide a participant perspective throughout the development of the project

Thank you for agreeing to this contract. I look forward to receiving your invaluable input through these sessions to help the development of this research up until the completion of the project in the year 2026.

Please sign below:

| [redacted] | 6//6/25 | [redacted] |
|---|---|---|
| Name of attendee | Date | Signature of attendee |
| Safiyyah Johal-Ayub | 09/06/25 | [redacted] |
| Name of facilitator | Date | Signature of facilitator |

# Appendix E

Minutes from PPI meeting

**Meeting Minutes**

**Date:** 19th May 2025
**Attendees:** Safi and [redacted]
**Purpose:** Planning interview questions, recruitment, and participant engagement

**Key Discussion Points**

1. **Interview Questions and Timing**
   - Concern that time constraints may make it difficult to cover all questions.
   - Consider selecting 8 of the most valuable questions.
   - Focus on 1–2 questions from the early sections, then spend the majority of the time on **culture and identity**.
2. **Interview Approach**
   - Avoid academic language; speak to participants as if conversing with a friend to build rapport.
   - Explain abbreviations in the first paragraph of documents and use consistently, with rationale provided.
   -
3. **Participant Support and Information**
   - Provide specific support organisations (e.g., Endo and Cysters).
   - Communicate the timeline clearly so participants know when they can read materials.
   - Inform participants about payment timing.
   - Ask if participants want to review their transcriptions; clarify that transcripts will be written out and may be long.
4. **Inclusivity Considerations**
   - Acknowledge trans and non-binary communities in the research.
   - Identify this area as needing further exploration.
5. **Recruitment Strategy**
   - Review Cysters Instagram recruitment posts for inspiration (e.g., carousel format with topic title, payment, contact information, number of participants, and screening process).

- Initial recruitment should attempt to proceed without Cysters, then approach Cysters if needed.
- Recruitment from places of worship may be more challenging.
- Send recruitment materials directly to Neelam.

**Changes to interview schedule:**

Add in :

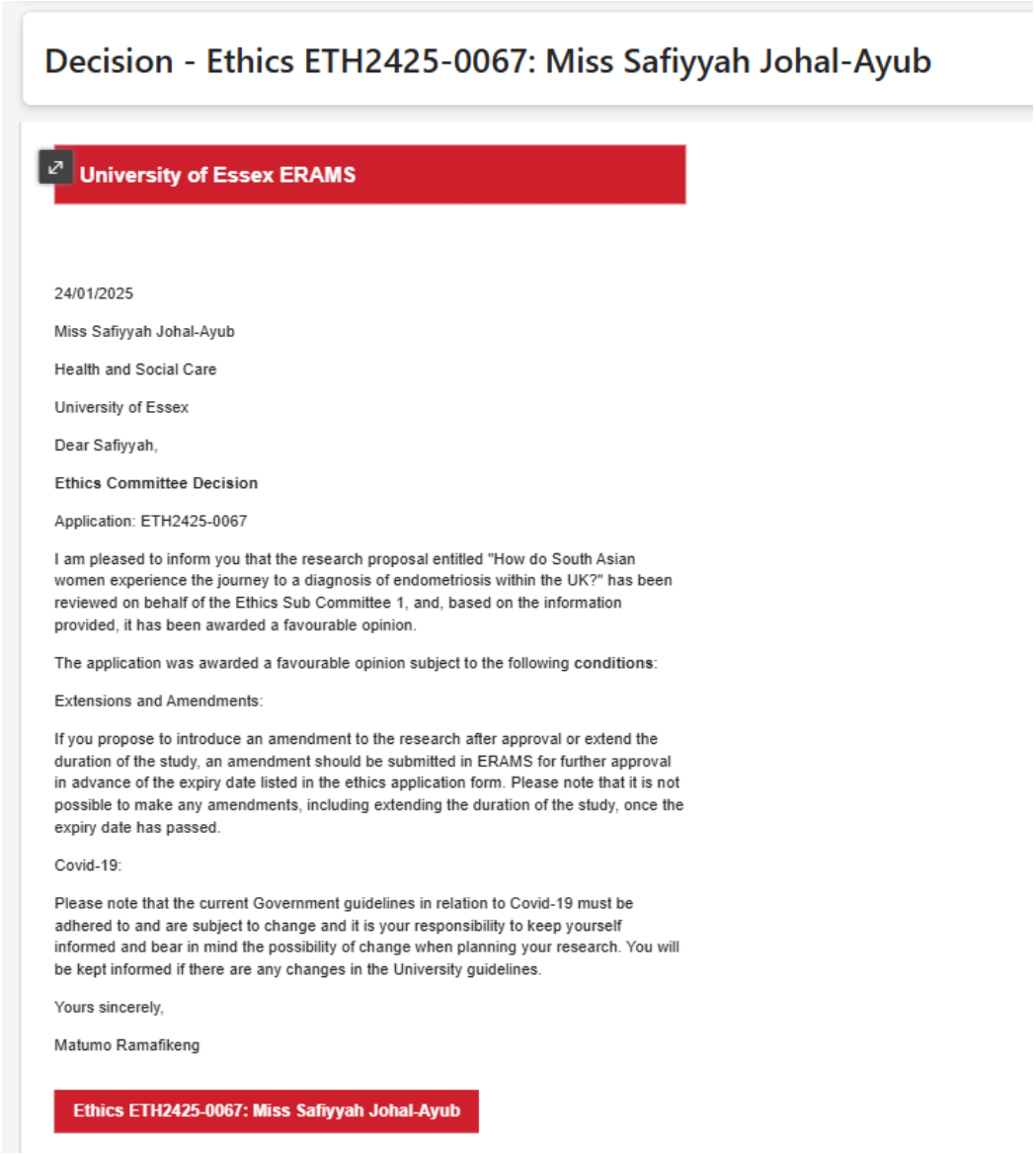
- Introduction- Start by telling people what you're doing with the research and what is/ isn't there already- help people to feel like they're contributing to something that hasn't been done before
- Feelings in the moment-Have you spoken to anyone about your endometriosis journey? (lots of people haven't told people they have endo)
- Support and identity- How accessible and culturally relevant are existing endometriosis support resources/ is there anything that would be helpful?

Changes:

- How does your culture play a part → Does your culture play a part

# Appendix F

Confirmation of ethical approval



Decision - Ethics ETH2425-0067: Miss Safiyyah Johal-Ayub

University of Essex ERAMS

24/01/2025

Miss Safiyyah Johal-Ayub

Health and Social Care

University of Essex

Dear Safiyyah,

**Ethics Committee Decision**

Application: ETH2425-0067

I am pleased to inform you that the research proposal entitled "How do South Asian women experience the journey to a diagnosis of endometriosis within the UK?" has been reviewed on behalf of the Ethics Sub Committee 1, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

Matumo Ramafikeng

Ethics ETH2425-0067: Miss Safiyyah Johal-Ayub

# Appendix G

Participant Information Sheet

University of Essex

**Participant Information Sheet**

**Project Title**

Exploring how South Asian women experience the journey to a diagnosis of Endometriosis with the UK

**Thesis research team**

Safiyyah Johal-Ayub, Trainee Clinical Psychologist

Jasmeet Kaur Bassi, Clinical Psychologist

Chris McCormack, Clinical Psychologist

My name is Safi Johal-Ayub and I am a Trainee Clinical Psychologist at the University of Essex. I would like to invite you to take part in my thesis research project. Before you decide whether or not to take part, it is important for you to understand why the research project is being done and what it will involve. Please take some time to read the following information carefully. If you would like to ask any questions before taking part, please email me at sj23185@essex.ac.uk.

**Purpose and aims of the study**

The research project investigates experiences of South Asian women who have a diagnosis of endometriosis who are over the age of 18 and living within the United Kingdom. This will be done through hearing your experiences of endometriosis and what this has meant for you. We will discuss this in an interview that will be held online or face to face, depending on your preference. It is my hope that this study will give South Asian women a safe and non-judgemental space to shed light and reflect upon their experiences. I hope that the findings from this research will help both physical health and mental health services have a better understanding of how to help young South Asian women who are seeking a diagnosis of endometriosis, and those who have a diagnosis. Your input in this study will have an influence in health professionals becoming better informed and learning what to look out for when working with South Asian women. This research project is being undertaken in relation to the Doctorate in Clinical Psychology. To make sure to get the best clarity of information about South Asian women with endometriosis experiences, I am looking to hear from those who already have a confirmed diagnosis of endometriosis by a medical professional.

University of Essex

**Why have I been invited to take part?**

You have been invited to participate in this research study due to reaching out after seeing the recruitment advertisement and meeting the participant criteria. This study has been advertised online through social media platforms, by charities and in community group halls and events.

**Participation**

It is your choice whether or not you wish to take part in this research project, your participation is completely voluntary. If you decide to take part, you will be asked to provide consent through signing a consent form. You are free to withdraw at any time by cancelling your interview or requesting to terminate the interview at any time for any reason and without explanation or penalty. Any data recorded up until your withdrawal will not be used.

If you decide to withdraw part way through your interview, your data will be discarded and not used in the research write-up.

Withdrawal of data would only be possible up to the point of termination of the online or face-to-face interview/data recording due to anonymization. If you wish to withdraw your participation, you can inform me via email at sj23185@essex.ac.uk.

**What will happen if I take part?**

If you decide you would like to take part in the study after reading this information sheet, you will be sent the consent form either via email or by post. If you then consent to taking part in the study, a convenient time will be arranged to meet, individually, with myself (Safiyyah) either online or face to face. If this call is online, you are welcome to have your camera off. The interview will last approximately 60-90 minutes, and there will be the option to conduct the interview over a few shorter meetings. You will be asked questions that relate to your endometriosis diagnosis. The interviews will be audio recorded, to aid with data analysis at a later stage. Once the transcription is completed, the original recording will be destroyed.

**How will I be paid?**

Everyone who takes part in the study will be paid with a £15 Amazon voucher. This will be sent to you via e-mail within a week of taking part in the study.

**Risks and benefits of the study**

Your participation will help with informing care for South Asian women. There are no anticipated risks to you taking part, neither is there any direct benefit to your physical or mental health, however, the nature of the conversations may be emotional and may cause some distress, but this is not expected as a direct risk. The researcher will make sure to regularly check in with how you are doing throughout the interview and you will be offered regular breaks and chances to pause. If any distress is identified the researcher will stop the interview and check with you whether you would like to continue. You can also stop the interview at any point by letting the researcher know you do not wish to continue. After all interviews a debrief will be offered. The researcher will also give you a list of support organisations that you can reach out to should you feel you need further support.

University of Essex

**What information will be collected?**

Information will be collected from our interviews through audio recordings of the conversation. The topics we will be talking about will include your stories and experiences of having endometriosis from when you first started experiencing symptoms, your healthcare encounters, diagnosis, the impact of the diagnosis and coping strategies. You will also be asked general demographic questions such as age and ethnicity. All the information that is collected will be anonymised.

**Confidentiality and data storage**

The information collected during this study will be treated as confidential. Your information will be anonymised and any identifiable information will be stored separately from your responses and redacted in transcription. Basic demographic information (e.g. age, ethnicity) will be anonymised and included in the final write-up. Quotes of your experiences may be used in the final write-up, but all the information enabling this to be identifiable will be removed.

All identifiable data will be used in the research study and will be electronically stored and retained securely until the end of the research project when it will be destroyed. The data will be stored securely and files will be encrypted or password protected. The anonymised data collected may be used to support other research in the future, and may be shared with other researchers. The anonymised transcripts and audio recordings will be deposited into The University of Essex Research Data Repository enabling them to be available for future research and learning activities. Our legal basis for processing your data is that you have consented to it. The Data Controller is the University of Essex; the University's Information Assurance Manager can be contacted on dpo@essex.ac.uk.

**What should I do if I want to take part?**

If you are happy to continue with participating in this research study, please read and sign the consent form provided and return it to me via email at sj23185@essex.ac.uk. If we agree to conduct the interview in person, you can bring this with you to our meeting.

Please contact me through the methods stated on the recruitment advertisement or on the social media platform on which you have seen the advertisement to express your interest in taking part and we can arrange for a phone call to discuss a time to meet for the interview.

**What will happen to the results of the study?**

The results of this study will be used in my doctoral thesis and will therefore be deposited in the Essex Open Access Research Repository.

There is also the hope that this research will be published as a journal article in a public academic journal. At this point, any results will be anonymised and so your data will not be identifiable. A copy of the findings of the study will be available for each participant should you want one.

**Who is funding the study?**

This research study is being funded by The University of Essex and is being conducted as part of the Doctorate in Clinical Psychology (DClinPsy).

University of Essex

**Who has reviewed the study?**

This study has been reviewed by Ethics Committee at the University of Essex Ethics Committee and been given a favourable ethical opinion.

**Complaints**

If you have any concerns or complaints about any aspect of the project, please contact the principal investigator of the research project, Safiyyah Johal-Ayub (sj23185@essex.ac.uk).

If are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal investigator, please contact the Essex University Director of Research Prof. Sheina Orbell (sorbell@essex.ac.uk), the Director of Research for the Department of Health and Social Care, Konstantinos Roussos (k.roussos@essex.ac.uk), or the Director of Postgraduate Research for the department of Health and Social Care Antonella Trotta (atrott@essex.ac.uk).

If you are still not satisfied, please contact the University of Essex Research Integrity Manager, Maryalena Sotiriadou (ms21994@essex.ac.uk). Please include the ERAMS reference which can be found at the foot of this page. Please do not hesitate to contact me should you have any further questions about the study.

Safiyyah Johal-Ayub - Trainee Clinical Psychologist sj23185@essex.ac.uk

Supervised by Jasmeet Kaur Bassi – Clinical Psychologist jb20603@essex.ac.uk

And

Chris McCormack- Clinical Psychologist cm18972@essex.ac.uk

Department of Health and Social Care,

University of Essex

Wivenhoe Park

Colchester

CO4 3SQ

**Appendix H**

Participant Screening form

Name: Age:

Do you speak English fluently? (Unfortunately, I am unable to provide an interpreter, and therefore fluent English is a requirement).

Do you identify as South Asian?

Yes / No

Do you have a medically confirmed diagnosis of Endometriosis (i.e. was it diagnosed by a doctor/ gynaecologist?)

Yes / No

Do you live in the UK?

Yes/ No

How long have you lived in the UK for?

_____years

How did you hear about the study?

Facebook

Instagram

Linkedin

Other, please specify

_____

# Appendix I

Participant Consent Form

University of Essex

Title of the Project: How do South Asian women experience their journey to a diagnosis of Endometriosis within the UK?

Research Team: Doctorate in Clinical Psychology, Department of Health and Social Care.

Please initial box

1. I confirm that I have read and understand the Information Sheet dated 02.09.2024 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty. I understand that any data collected up to the point of my withdrawal e.g. will be destroyed; cannot be withdrawn because it cannot be identified. ☐
3. I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. ☐
4. I understand that my fully anonymised data will be used for thesis write-up, presentations and research publications. ☐
5. I understand that the data collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
6. I give permission for the transcripts and audio recordings that I provide to be deposited in The University of Essex Research Data Repository so that they will be available for future research and learning activities by other individuals. ☐
7. I agree to take part in the above study. ☐

| Participant Name | Date | Participant Signature |
| --- | --- | --- |
| _____ | _____ | _____ |

| Researcher Name | Date | Researcher Signature |
| --- | --- | --- |
| _____ | _____ | _____ |

# Appendix J

Interview Schedule

Ethics ETH2425-0067:

Interview schedule: potential questions to be asked.

Section 1: Introduction and building a relationship

- Introduce self and background.
- Discuss the research in general, including the reason for the study, gaps in the literature and hopes for future research.

Section 2: Feelings in the moment

- Have you told anyone that you have endometriosis?
- Have you spoken to anyone about your endometriosis journey? (lots of people haven't told people they have endo)
- How do you feel talking about it today?
- How do you currently feel about the diagnosis? Has this changed over time?

Section 3: Symptoms

- When did you first start experiencing symptoms?
- What symptoms do you experience?
- Have your symptoms changed over time?
- Which symptoms do you struggle with the most?

Section 4: Experiences of healthcare systems

- How have you experienced the healthcare systems in relation to your diagnosis?
- Have you had any experiences that stand out? What was it about them that made them stand out?
- Do you feel your identity has impacted these experiences?

Section 5: Endometriosis within the system

- Does it affect your relationships? And if so, how does it affect your relationships?
- Do your friends and family understand endometriosis? If so, what is their understanding?
- Have you disclosed your diagnosis to your employers? Does it affect your work?
- How does you work place understand it?

Section 6: Support and identity

- What support do you need and you use?
- Does your culture play a part in how you cope?
- How accessible and culturally relevant are existing endometriosis support resources/ is there anything that would be helpful?
- Is there any part of your South Asian heritage that's important for you to draw strength upon?

# Appendix K

Sample of an analysed transcript

21/07/2025

Transcript Participant 18
(57m 9s)

Researcher started transcription

Researcher: OK so ermm. I've got some questions for you, but also I want to hear about your experiences. So erm, if you feel you want to say you know more than what I've asked or less, erm or you, you feel there's something else you feel is important to talk about, then that's absolutely fine.

PP: OK.

Researcher: Yeah. Um. So I guess I wondered first of all, have you told anyone that you have any endometriosis?

PP: I haven't really spoken about endometriosis to anyone apart from my General practitioner, erm, a few people in my family member, my family know about it, so I kind of spoke a little bit about it, you know, because I didn't expect them to understand what endometriosis is all about. Yeah. At the same time, it wasn't easy at all. You know, I at first I I had to keep it to myself because in my culture, you know, topics like period or you know, anything related to health reproductive health are, you know, really not spoken about openly. Yeah, sometimes even with close family. I felt ashamed, like I was, you know, complaining too much of being dramatic. But I've been able to, you know erm, open up and talk to a few people about it.

Commented [SJ1]: Cultural script around women's health being taboo/ silenced.
Brings in emotive language to demonstrate the impact of this.
Family and GP introduced

Researcher: OK. So it sounds like erm, it was it was difficult to start with, to talk to people about it, but there's a few people now that you have spoken to.

PP: Definitely.

Researcher: Yeah, OK. And how do you feel talking about your endometriosis today?

PP: What do you say?

Researcher: How do you feel talking about it today?

PP: Ermm. Well, since I've already talked about endometriosis with erm, you know, erm, a few people, my GP, I feel OK to, you know, to talk about erm endometriosis.

Researcher: OK-

PP: -It's OK to talk about it.

Researcher: And how do you feel about your diagnosis?

PP: Well, I feel erm…I feel more confident. You know, 'cause, I've been able to. I've. I've been believed. You know, I feel relieved, you know, to finally have a name for what I've been going through for years. I was in pain and erm it felt like no one believed me, you know, not even doctors? Sometimes. So getting a diagnosis, you know, made me feel, you know, validated like I wasn't imagining things and you know, my pain had a real

cause, you know. But at the same time, I also feel angry and frustrated because, you know, it took me so long to get here. I kept thinking, you know, if someone had listened earlier, maybe things wouldn't have gotten this bad. You know, there's also sadness to, especially when I think about it, how it affects you know, things like fertility, energy levels and just being able, you know, to live life normally.

Researcher: Umm, Yeah. So it sounds like it's had quite a big impact on you.

PP: Sure.

Researcher: And erm so you spoke a little bit about the pain and a few other symptoms there. But I guess I was wondering when you first started experiencing symptoms and if you could tell me a little bit about your journey to getting a diagnosis?

PP: Ermm, well, I would be happy to do that. You know, I first noticed, you know something wasn't right in my late teens, maybe around the time I started my period, you know, from the very beginning, my period were extremely painful, not just cramps, you know, but erm that kind of pain that would make me know sometimes vomit or, you know, faint. I couldn't stand or breath sometimes, but I was told it was normal and up, you know, all girls go through this so I just got tired, you know? And I just tried to cope. So as I got older, you know, the symtpoms got worse. I started experiencing chronic pelvic pain not just during my period, but even between my cycles. You know, I would feel erm a deep, aching pain in my lower back and legs and sometimes during erm sex as well, you know, which was really confusing and difficult to talk about.

Researcher: Umm. How old were you when you start first started experiencing those symptoms?

PP: I was in my last teens then I think I was 17. Yeah, I was 17 then. You know, I started experiencing erm those symptoms. I really didn't know what was happening. Yeah, 'cause. I was. I just thought something was wrong with me. Yeah, but I couldn't explain.

Researcher: Mm-hmm. And so how did you end up going to your GP? Because you mentioned that you've spoken to your GP about it?

PP: You know, it took me a really long time before I finally went to the GP. Yeah, I I think I reached a breaking point. You know, the pain, you know, started interfering with my everyday life. I was, you know, missing work. I was cancelling plans and, you know, constantly feeling exhausted, you know? There were days I couldn't stand for long or work properly because erm the pain was so intense at a point I, you know, I had a really heavy period that left me dizzy and dreamt. And you know, I was really scared because I remember thinking, yeah, this can't just be normal. Yes. So it was erm after these experiences that, you know, I finally got to speak with a GP when I spoke to my GP I tried to explain everything, you know? But I still had to push how, you know, a little bit to be heard, you know, at first I thought that I I might just be having, you know, bad periods or stress. I had to go back, you know, a few times before the, you know, referred me to a specialist. I was, you know, erm frustrated, you know, I almost gave up or, you know, I'm glad that I kept going, even though it took me time because. And that's how I started. I finally started getting the, you know, answers I needed.

Researcher: Uh-huh. And you mentioned you had to go to the GP quite a few times, but I'm wondering and because you said that talking about periods was erm... quite difficult for you in your in your culture, so I'm wondering how that was speaking to the GP about it?

PP: Yeah. Sorry, you were breaking. Can you ask the question again?

**Commented [SJ2]:** Diagnosis as a turning point in her story- allowing for recognition and being believed
Diagnosis as validation
Emotive language used- sadness, frustration and anger as well as confident and relieved.
Re-storying the past- reflecting on what she has lost out on due to endometriosis
Reflecting on the impact on general life in different areas

**Commented [SJ3]:** Story starts with returning to her first period- acknowledges knowing something wasn't right from the start.
Pain mentioned repeatedly- also mentioned above- this keeps being returned to.
"told it was normal"- symptoms being normalised by others
Symptoms experienced in her full body
Emotive language- discusses confusion

**Commented [SJ4]:** Know's something wasn't right but was unsure what- internalised and felt this was something wrong with herself.
Couldn't explain- lacks the language

**Commented [SJ5]:** Metaphor of reaching "breaking point".
Pain is returned to again.
uses a list to show how many things are affected.
Emotive language used again e.g. scared
Again questioning the idea of this being labelled as normal- once this has been said it is running through her narrative.
Had to "push"- taking on autonomy for the difficulties experienced due to lack of answers or action from the GP
This story centres around her interactions with the GP and why she ended persisting.

Researcher: Yeah, I'm wondering how it was talking to the GP about your experiences because you said that in your culture, it's difficult to talk about periods and that type of thing.

PP: Well, it was really difficult, you know, but when the pain got so erm intense, I had to, you know, um, talking to the GP was erm actually really uncomfortable at first because of how I was brought up in my culture. We really do not talk about period. Or anything you know that has to do with reproductive health. Even saying the word period out loud can feel awkward or shameful. So, you know, trying to describe really personal, painful symptoms to a stranger, especially if they were male, felt embarrassing and erm exposing so.
It was really tough, you know, to open up at first, but I had to push myself because I knew something wasn't right and I couldn't, you know, keep suffering in silence.

Researcher: Mm-hmm. And you, you also mentioned that erm…you had to go back to the GP lots of times.

PP: Sure.

Researcher: How, how was that experience of having to keep going back?

PP: You know, having to keep going back to GPs so many times was really frustrating you know, I I was honestly drained, you know. You know, because each time I went, I had to repeat the same story. Explain the same symptoms and try to convince them erm that the pain wasn't normal. Erm, after a while I started to feel like I wasn't being taken seriously like erm they thought I was, you know, exaggerating, or, you know, blowing things out of proportion, you know? So erm, there were a few times I left the appointment, you know, feeling defeated like I was, you know, wasting their time. Sometimes, sometimes I would we be told to try a new painkiller or go on the pill, you know, without anyone actually investigating the cause. And with each delay, you know, my symptom just got worse. Yeah, so eventually I got referred to a specialist and you know that only happened because, you know, I kept pushing, you know, it shouldn't have to be like that, you know, no one should have to fight too hard to be believed.

Researcher: Mmm. So you said that you feel like they didn't believe you?

PP: Sure. Yeah.

Researcher: Why? Why do you think that was?

PP: Well, 'cause, erm, they kept telling me that it was a normal period. You know, I I just feel like erm they really do not understand endometriosis. They were telling me it's normal. It is what every girl go through and I have to endure, I have to try new pain killers. You know I have to, you know, try new things. Yeah. So I feel like they didn't just want, they just felt like I was erm, you know, exaggerating. Like I already said.

Researcher: Mmm. OK. And so you said that eventually you were referred to a specialist.

PP: Sure.

Researcher: Can you tell me about that experience and how that happened and what happened when you went to them?

**Commented [SJ6]:** Cultural script around shame and women's health is returned to.
Gender is brought into this story- GP being male
Emotive language of how this gender and culture imbalance affects her "awkward and shameful" as well as "embarrassing"
Metaphor of "suffering in silence" to highlight the impact of this

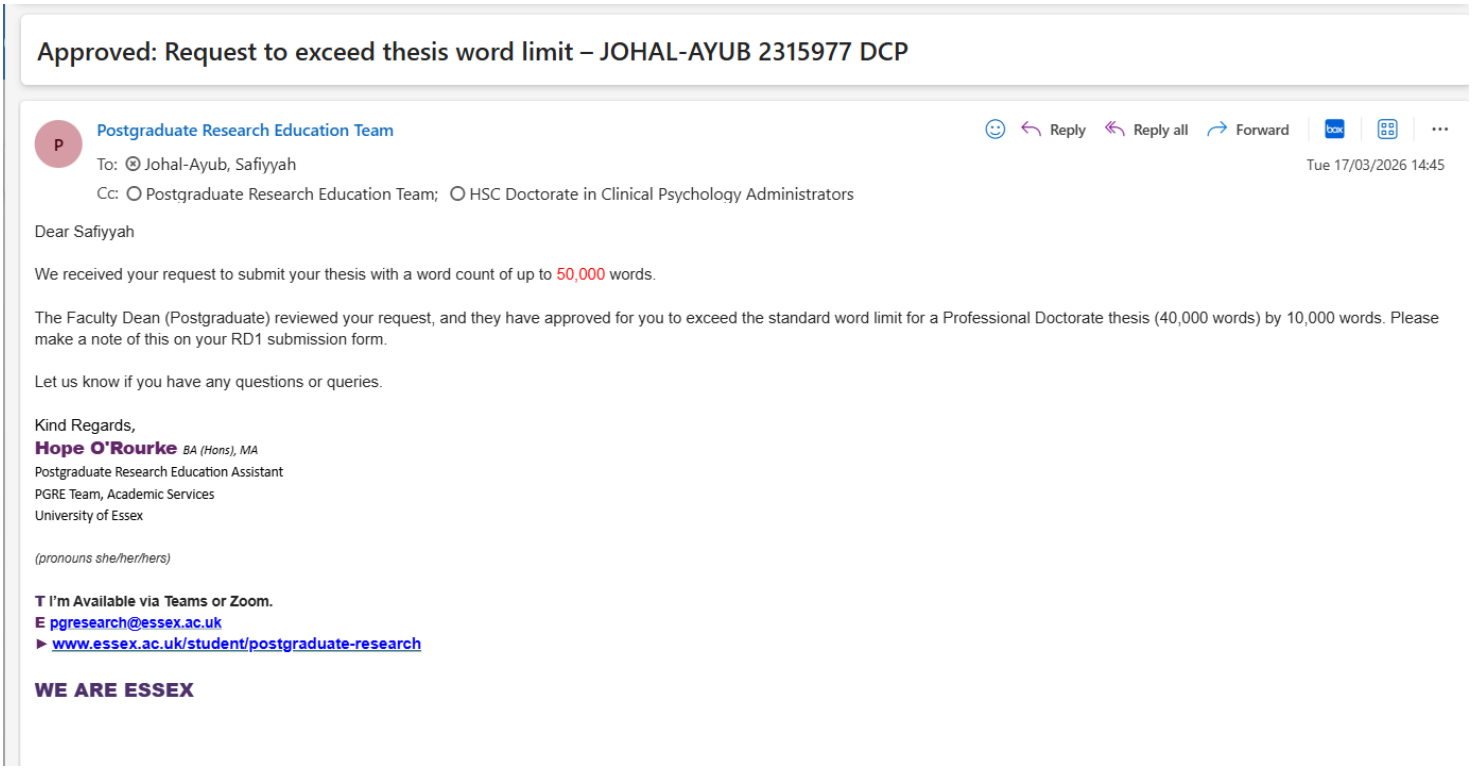
**Commented [SJ7]:** Identifies the impact of delay- increase in symptoms.
Only referred to the specialist because kept pushing- advocating for self.

**Commented [SJ8]:** Introduces the idea of repetition/ circular narrative and the impact this has- emotive e.g. draining. Fits Franks idea of chaos narratives where there is lack of control.

**Commented [SJ9]:** Being told it is a "normal period" is now interpreted as a lack of knowledge from the GP around endometriosis.
Returned to the idea of "exaggerating"- External interpretation labelled

# Appendix L

Word Count Extension Approval to 50,000 words



Approved: Request to exceed thesis word limit – JOHAL-AYUB 2315977 DCP

P

Postgraduate Research Education Team

Reply | Reply all | Forward

To: Johal-Ayub, Safiyyah

Tue 17/03/2026 14:45

Cc: Postgraduate Research Education Team; HSC Doctorate in Clinical Psychology Administrators

Dear Safiyyah

We received your request to submit your thesis with a word count of up to 50,000 words.

The Faculty Dean (Postgraduate) reviewed your request, and they have approved for you to exceed the standard word limit for a Professional Doctorate thesis (40,000 words) by 10,000 words. Please make a note of this on your RD1 submission form.

Let us know if you have any questions or queries.

Kind Regards,

**Hope O'Rourke** *BA (Hons), MA*

Postgraduate Research Education Assistant

PGRE Team, Academic Services

University of Essex

*(pronouns she/her/hers)*

**T I'm Available via Teams or Zoom.**

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