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**Understanding The Psychosocial Impact of
Endometriosis-Related Persistent Pain in Aotearoa New Zealand**

A thesis submitted in fulfilment
of the requirements for the degree
of
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at
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Estie-Lomé Mouton



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Abstract

Endometriosis-related persistent pain is often understood through biomedical frameworks focused on diagnosis, lesions, surgery, and symptom management. However, persistent pain also has emotional, cognitive, social, relational, and healthcare-mediated dimensions that shape how pain is lived and made meaningful over time. This qualitative study explored the psychosocial factors, dynamics, and processes that shape the lived experience of endometriosis-related persistent pain among women in Aotearoa New Zealand. In particular, it examined how emotional distress, meaning-making, interpersonal relationships, social recognition, support, and healthcare experiences influenced the ways in which pain was understood, managed, and lived with. The study was informed by a biopsychosocial understanding of persistent pain and sensitised by feminist health perspectives on gendered pain, legitimacy, and healthcare dismissal. Thirteen women with clinically diagnosed endometriosis and endometriosis-related persistent pain participated in in-depth semi-structured interviews. Data were analysed using reflexive thematic analysis. Five themes were developed: “No amount of pain should be normal”: struggling to legitimise pain; Waiting in pain: care pathways, uncertainty, and the cost of access; Living with an unpredictable and invisible body; Carrying pain internally: distress, self-doubt, and self-compassion; and Making pain liveable: support, relief, and whole-person care. Together, these themes showed an analytic movement from pain being questioned, to pain being prolonged, socially managed, internally carried, and made more liveable. Participants’ accounts showed that persistent pain was not only endured in the body, but also negotiated through healthcare systems, relationships, social expectations, internal

meaning-making, and access to support. The findings suggest that endometriosis-related persistent pain cannot be understood through symptom severity, diagnosis, or treatment history alone. Instead, it is shaped by recognition, waiting, invisibility, distress, self-trust, and the forms of care and support that help restore agency, participation, and liveability.

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Chapter One: Introduction

Chapter Overview

Endometriosis-related persistent pain is often understood primarily through biomedical frameworks, particularly in relation to diagnosis, lesions, surgery, and symptom management. However, persistent pain also has emotional, cognitive, social, relational, and healthcare-mediated dimensions. For people living with endometriosis, pain can shape not only bodily functioning, but also identity, relationships, work, study, social participation, mental wellbeing, and experiences of recognition or dismissal within healthcare systems.

This thesis explores the psychosocial factors, dynamics, and processes that shape the lived experience of endometriosis-related persistent pain in Aotearoa New Zealand. Drawing on in-depth semi-structured interviews with 13 women, the study examines how participants understood, managed, and made sense of persistent pain across personal, social, and healthcare contexts. The research is informed by a biopsychosocial understanding of persistent pain and sensitised by feminist health perspectives on gendered pain, legitimacy, and healthcare dismissal.

This chapter introduces the background and rationale for the study. It begins by outlining endometriosis-related persistent pain as a significant embodied and psychosocial experience. It then situates the study within the Aotearoa New Zealand context, with attention to diagnostic delay, healthcare access, and the need for whole-

person understandings of pain. The chapter concludes by situating the study within the Aotearoa New Zealand context and providing an overview of the thesis structure.

Background to the Study

Endometriosis is a chronic inflammatory condition in which tissue similar to the lining of the uterus is found outside the uterus, causing inflammation, scar tissue formation, or adhesions. It is most commonly found in the pelvis, including on the pelvic peritoneum, ovaries, bladder, bowel, and surrounding structures. However, endometriosis can also occur outside the pelvis, including in the abdomen, chest, abdominal wall, muscles, joints, peripheral nerves, and, in rare cases, the central nervous system (The Endometriosis Network Canada, n.d.; World Health Organization [WHO], 2025). Symptoms can include severe menstrual pain, chronic pelvic pain, pain during or after sex, bowel and bladder symptoms, fatigue, infertility, abdominal bloating, nausea, and reduced quality of life.

Endometriosis is estimated to affect approximately 190 million people globally, often reported as around 10% of reproductive-age women and girls (WHO, 2025). Despite this prevalence, endometriosis remains under-recognised in healthcare systems, public health policy, and everyday understandings of menstrual and pelvic pain. A global scoping review of endometriosis policy found that only Australia and France had stand-alone national endometriosis action plans, highlighting the limited policy infrastructure available internationally despite the condition's prevalence and socioeconomic impact (Gibbons et al., 2025).

Although endometriosis is often discussed as a gynaecological condition, its effects can extend far beyond the reproductive system. Individuals with endometriosis-related pain can experience reduced quality of life, impaired mental wellbeing, social isolation, disruptions to work or education, and financial strain (WHO, 2025). For many people, endometriosis-related pain affects daily functioning, emotional wellbeing, relationships, healthcare engagement, and future planning.

Persistent pain associated with endometriosis is complex. Pain may be related to endometriotic lesions, inflammation, adhesions, surgery, nerve involvement, pelvic floor dysfunction, central sensitisation, or other overlapping pain mechanisms. Importantly, the severity of pain does not always correspond neatly with the visible extent or classification of disease. Existing classification systems have limited correlation with pain symptoms and quality of life, meaning that disease stage or visible lesions cannot fully explain how pain is experienced or how much it affects a person's life (Johnson et al., 2017).

In this thesis, the term 'persistent pain' is used to refer to pain that persists, recurs, or continues to shape everyday life over time. This terminology overlaps with clinical definitions of chronic pain, which is commonly defined as pain that persists or recurs for longer than three months (International Association for the Study of Pain, n.d.). It also relates to chronic pelvic pain, which is often defined more specifically as pelvic pain occurring on most or all days for more than six months and not associated with pregnancy. (Tewhaiti-Smith et al., 2025). However, the term persistent pain is used here because participants' pain was not always limited to the pelvis, nor was it always continuous in a simple or predictable way. For some participants, pain was cyclical, recurrent, flare-

based, non-cyclical, post-surgical, nerve-related, or associated with wider bodily symptoms. The term persistent pain therefore better captures the ongoing, disruptive, and lived nature of endometriosis-related pain without reducing it to a single location, pattern, or clinical category.

There is currently no definitive cure for endometriosis, and symptoms may persist or recur after treatment has begun (WHO, 2025). Some people continue to experience pain after diagnosis, hormonal treatment, surgery, or lesion removal. This means that endometriosis-related persistent pain cannot be fully understood through disease visibility, staging, or lesion-focused explanations alone.

For this reason, persistent pain requires attention to both its embodied reality and its psychosocial context. Pain is not “just physical” or “just psychological.” Rather, it is lived through the body while also being shaped by emotional distress, self-doubt, uncertainty, social support, stigma, healthcare access, and experiences of being believed or dismissed. A biopsychosocial approach is therefore useful because it allows persistent pain to be understood as a whole-person experience shaped by interactions between biological, psychological, and social dimensions.

A note on terminology is important. Endometriosis is commonly associated with people assigned female at birth and is frequently discussed in the literature in relation to women’s health. However, not all people with endometriosis identify as women, and inclusive terminology is important when referring to endometriosis more broadly. Throughout this thesis, terms such as “people with endometriosis” and “individuals with

endometriosis” are used to refer to the condition in general. The term “women” is used to refer to the participants in this study, as all participants identified as women and referred to themselves in this way, and to discuss literature that specifically refers to women. This wording is intended to recognise gender diversity while accurately representing the study sample and the terminology used in much of the existing literature.

This study focuses specifically on the psychosocial experience of endometriosis-related persistent pain. It does not aim to represent all experiences of endometriosis, nor does it suggest that all people with endometriosis experience persistent pain in the same way. Instead, it examines how women in Aotearoa New Zealand who live with endometriosis-related persistent pain describe the impact of pain on their lives, how they make sense of that pain, and what forms of recognition, support, care, and self-understanding make pain more liveable.

Endometriosis-Related Persistent Pain as a Psychosocial Experience

Endometriosis-related persistent pain is not experienced only as a physical sensation. It can shape how people understand their bodies, how they relate to others, how they participate in work or study, how they seek care, and how they make sense of uncertainty. Pain may interrupt everyday routines, restrict social participation, affect intimate relationships, and create distress when symptoms are unpredictable, invisible, or difficult for others to understand. For this reason, the impact of persistent pain cannot be captured fully by measuring symptom severity alone.

A central psychosocial issue in endometriosis-related pain is legitimacy. Many people with endometriosis describe pain that is normalised, minimised, or dismissed before diagnosis. Severe menstrual or pelvic pain may be interpreted as ordinary, exaggerated, psychological, or something to endure. When pain is invisible or unsupported by clear test results, people may be required to repeatedly justify their experiences to family members, peers, employers, and healthcare professionals. These processes can shape self-trust, help-seeking, and emotional wellbeing, as pain becomes something that must be both proven and endured.

Healthcare experiences are equally important to the psychosocial dimensions of persistent pain. Delays in diagnosis, long waits for treatment, fragmented communication, and limited access to specialist or multidisciplinary care can prolong uncertainty and distress. For some people, private healthcare, insurance, family support, health literacy, or flexible work arrangements may increase agency or shorten waiting times. For others, financial barriers and limited public options may leave pain unmanaged for long periods. In this way, care pathways do not simply respond to pain; they can shape how pain is lived, interpreted, and managed over time.

Persistent pain simultaneously affects social life because it is often unpredictable and invisible. People may appear well while experiencing severe symptoms, which can make pain difficult for others to recognise. This invisibility can create pressure to explain, disclose, mask, or perform normality. Social and workplace participation may become conditional on whether pain can be hidden, planned around, or made understandable to others. As a result, persistent pain can produce social labour as well as physical limitation.

The internal impact of persistent pain is equally significant. Repeated dismissal, uncertainty, disrupted identity, and reduced participation can contribute to distress, guilt, self-doubt, rumination, grief, and fear about the future. At the same time, people may develop ways of making pain more liveable through support, self-compassion, acceptance, pain relief, psychological care, information, and more responsive healthcare relationships. Understanding persistent pain psychosocially, therefore, requires attention not only to suffering but also to the forms of care, recognition, agency, and support that help people continue living meaningful lives.

This study approaches endometriosis-related persistent pain as embodied, socially situated, and healthcare-mediated. It examines how pain is made meaningful through personal experience, interpersonal relationships, social recognition, and healthcare encounters. This framing supports a whole-person understanding of pain and provides the basis for the research problem and rationale outlined in the following sections.

Aotearoa New Zealand Context

This study is situated in Aotearoa New Zealand, where both individual experiences and healthcare system contexts shape endometriosis-related persistent pain.

Endometriosis New Zealand estimates that endometriosis affects approximately 120,000 people in Aotearoa New Zealand, or roughly 1 in 10 girls, women, and people assigned female at birth. Despite this prevalence, endometriosis remains under-recognised, misunderstood, and under-prioritised within the health system (Endometriosis New Zealand, n.d.).

For many people, the pathway to diagnosis and care involves general practice, referrals, imaging, specialist assessment, public waitlists, private healthcare options, and ongoing symptom management. These pathways can shape not only whether people access care, but also how long they remain in pain, how much uncertainty they carry, and how supported or dismissed they feel while seeking help. Endometriosis New Zealand identifies an average delay from symptom onset to diagnosis of nearly ten years in Aotearoa New Zealand, alongside long waits for specialist care, inconsistent access to treatment, and inequitable barriers for Māori, Pasifika, and rural communities (Endometriosis New Zealand, n.d.). Peer-reviewed evidence on diagnostic delay and variation across cohorts is discussed in more detail in Chapter Two.

The burden of endometriosis and chronic pelvic pain in Aotearoa New Zealand is also economic. A recent nationwide cost-of-illness study estimated that endometriosis and chronic pelvic pain impose a substantial annual macroeconomic burden, ranging from approximately NZD 22.6 billion to NZD 31.7 billion depending on prevalence assumptions (Tewhaiti-Smith et al., 2025). Productivity losses were the primary cost driver, accounting for 65% of endometriosis-related costs and 75% of chronic pelvic pain costs. These findings highlight that endometriosis-related persistent pain affects not only individual wellbeing, but also employment, productivity, caregiving, healthcare use, and broader social participation.

Additionally, the Aotearoa New Zealand context raises important questions about policy and service coordination. Endometriosis New Zealand is currently advocating for a National Endometriosis Action Plan focused on education and awareness, clinical

management and care, and research and innovation. This advocacy is significant because international policy work has identified national action plans as one way to coordinate awareness, clinical care, research, and accountability. Australia launched the world's first National Action Plan for Endometriosis in 2018, with France following in 2022, while global policy review evidence suggests that stand-alone endometriosis national action plans remain rare internationally (Endometriosis New Zealand, n.d.; Gibbons et al., 2025).

Furthermore, the Aotearoa New Zealand context raises important concerns about equity. Access to timely, validating, and culturally safe care is not evenly distributed. Māori, Pasifika, migrant, rural, and financially constrained patients may face particular barriers when seeking recognition and treatment for endometriosis-related pain (Dunning et al., 2025; Ellis, Tewhaiti-Smith, et al., 2024; Endometriosis New Zealand, n.d.). Although this study does not claim to provide a comprehensive analysis of ethnic inequity or health-system access, it recognises that persistent pain is lived within broader social and structural conditions. These conditions can influence whether pain is believed, how quickly care is accessed, and what forms of support are available.

Understanding endometriosis-related persistent pain in Aotearoa New Zealand therefore requires attention to more than diagnosis and treatment. It requires consideration of how healthcare pathways, costs, waiting times, cultural and social expectations, and access to support shape the lived experience of pain. This study contributes to that understanding by exploring how women in Aotearoa New Zealand describe the psychosocial impact of persistent pain and the conditions that make pain harder or more possible to live with.

This chapter has introduced endometriosis-related persistent pain as an embodied and psychosocial experience situated within the Aotearoa New Zealand context. The following chapter reviews literature relevant to the clinical complexity, psychosocial impact, social recognition, healthcare pathways, internal burden, and whole-person care of endometriosis-related persistent pain. This literature review provides the basis for the research problem, gap, aim, questions, and objectives presented at the end of Chapter Two.

Overview of the Thesis

This thesis is organised into five chapters. Chapter One has introduced the background and context of the study. It has outlined endometriosis-related persistent pain as an embodied and psychosocial experience shaped by emotional, cognitive, social, relational, and healthcare-related dimensions within Aotearoa New Zealand.

Chapter Two reviews literature relevant to endometriosis-related persistent pain. It examines clinical understandings of endometriosis and persistent pain before considering psychosocial dimensions such as pain legitimacy, diagnostic delay, stigma, social participation, emotional distress, self-doubt, support, and whole-person care. The chapter concludes by identifying the research problem, research gap, study aim, research questions, and objectives.

Chapter Three outlines the methodology used in the study. I discuss the qualitative research design, researcher positionality and reflexivity, participant recruitment, participant characteristics, ethical considerations, data collection through in-depth semi-

structured interviews, reflexive thematic analysis, and strategies used to support methodological integrity.

Chapter Four presents the findings and discussion together. The chapter is organised around five themes: “No amount of pain should be normal”: struggling to legitimise pain; Waiting in pain: care pathways, uncertainty, and the cost of access; Living with an unpredictable and invisible body; Carrying pain internally: distress, self-doubt, and self-compassion; and Making pain liveable: support, relief, and whole-person care. Together, these themes show how endometriosis-related persistent pain was questioned, prolonged, socially managed, internally carried, and made more liveable.

Chapter Five concludes the thesis by synthesising the study’s key findings and contributions. The implications of the research for endometriosis care are considered, including persistent pain support, healthcare communication, psychosocial recognition, and future research. The chapter also discusses the strengths and limitations of the study before offering a final reflection on the importance of recognising endometriosis-related persistent pain as real, embodied, socially situated, and deserving of whole-person care.

Chapter Two: Literature Review

This literature review investigates endometriosis-related persistent pain as a psychosocial, embodied, socially situated, and healthcare-mediated phenomenon. Instead of offering a comprehensive overview of endometriosis, this chapter analyses literature that contextualises how persistent pain is recognised, delayed, socially managed, internally experienced, and made more liveable. This study does not aim to represent all experiences of endometriosis. Rather, it focuses specifically on people who experience persistent pain associated with endometriosis, while recognising that some people with endometriosis may receive timely diagnosis, effective treatment, or may not experience persistent pain in the same way. This approach supports the aim of the present study: to examine how endometriosis-related persistent pain shapes people's lives, identities, relationships, and experiences of care in Aotearoa New Zealand.

Research demonstrates that endometriosis is associated with pain and diminished health-related quality of life (Kalfas et al., 2022). Consequently, endometriosis-related pain should be understood not only as a symptom, but as an experience with broader implications for wellbeing. Endometriosis-related pain and other symptoms may affect women's relationships with their bodies, psychological and social wellbeing, life plans, and everyday functioning (de C Williams & McGrigor, 2024). These findings support the perspective that persistent pain is both physically real and psychosocially shaped.

This chapter reviews literature relevant to understanding endometriosis-related persistent pain, including biological pain mechanisms, diagnostic uncertainty, treatment

limitations, gendered dismissal, social recognition, emotional distress, support, and access to care. The chapter first establishes why endometriosis-related persistent pain cannot be fully explained by a biomedical model. It then addresses the psychosocial impact of pain, followed by an examination of how pain may be questioned, prolonged, socially managed, internally experienced, and made more liveable. This review establishes the foundation for a qualitative and interpretive analysis of how women in Aotearoa New Zealand understand and manage persistent pain associated with endometriosis.

Endometriosis-Related Persistent Pain: Beyond a Purely Biomedical Model

This section provides a focused clinical background to establish that endometriosis-related pain is embodied and materially real, while also demonstrating why a purely biomedical or lesion-focused understanding is insufficient. Although much clinical literature refers to chronic pelvic pain, this thesis uses the term endometriosis-related persistent pain to acknowledge that endometriosis is not solely a gynaecological or pelvic condition, and that pain may be persistent, recurrent, multi-site, and shaped by biological, psychological, social, and healthcare contexts.

Endometriosis is a chronic condition for which there is currently no medical or surgical cure, and pain is central to many people's experience of the disease. As-Sanie et al. (2025) report that approximately 90% of people diagnosed with endometriosis experience pelvic pain, indicating that pain is not a peripheral concern but one of the main ways the condition is lived and recognised.

Importantly, As-Sanie et al. describe endometriosis-related pain as clinically complex, explaining that pain may involve nociceptive, neuropathic, and nociplastic mechanisms. Nociceptive pain refers to pain associated with tissue damage, inflammation, or irritation. Neuropathic pain involves injury or dysfunction in the nervous system. Nociplastic pain refers to altered pain processing where pain persists or becomes amplified even when it is not fully explained by ongoing tissue damage. This distinction is significant for the present study because it helps explain why pain may persist, recur, or spread beyond what can be explained by visible lesions alone. It also supports the view that persistent pain is not simply a direct reflection of disease stage, imaging, or surgical findings.

The weak relationship between visible disease and pain severity further complicates a purely biomedical model. As-Sanie et al. further argue that the severity of pelvic pain does not necessarily correlate with the number, location, or subtype of endometriosis lesions. Their review indicates that not all patients respond to lesion-focused treatments, and that pain can recur without clear evidence of recurrent lesions. This evidence is particularly relevant because it challenges the assumption that treating lesions alone will necessarily resolve pain. For some women, lesion-focused treatment may be important and beneficial; however, for others, persistent pain may continue to affect daily life even after medical or surgical intervention.

This complexity provides a rationale for adopting a biopsychosocial understanding of endometriosis-related persistent pain. Individuals with similar disease presentations may experience different levels of pain, distress, impairment, and quality-of-life impact.

Psychosocial and biological factors interact to produce diverse pain experiences, and research on persistent pain demonstrates the influential, interactive role of psychosocial factors in pain (Kalfas et al., 2022; Pickup et al., 2025). A biopsychosocial framework is therefore particularly useful because it does not deny the biological reality of endometriosis pain, but recognises that pain is also shaped by emotional, cognitive, relational, social, and healthcare contexts.

The COMPASS model (*A COmprehensive Model of Pain encompassing Agency, Systemic factors and Sense making*) proposed by Pickup et al. (2025) reinforces this broader perspective by conceptualising endometriosis-related persistent pain as shaped by the interaction of individual, interpersonal, healthcare, and systemic factors. Rather than locating pain management solely within the body or the individual, the model highlights the role of agency, sense-making, health literacy, validation, access to care, and wider healthcare systems. This is useful for the present study because it supports an understanding of persistent pain as embodied and socially situated, shaped by how symptoms are interpreted, responded to, and managed within everyday life and healthcare contexts.

Similarly, Åkerblom et al. (2026) argue that a multidimensional biopsychosocial approach is valuable for understanding endometriosis and for informing future targeted interventions. Taken together, this literature suggests that endometriosis-related persistent pain requires more than a biomedical account of disease pathology. It requires attention to the interaction between bodies, emotions, meanings, relationships, healthcare encounters, and broader systems of care.

Psychosocial Impact and Quality of Life

Building on the need for a biopsychosocial understanding, research has consistently shown that endometriosis-related symptoms can affect quality of life across multiple domains. As explained above, pain and pain-related distress do not appear to be explained by disease stage alone, suggesting that psychosocial factors may play a role in shaping the pain experience (Aerts et al., 2018; As-Sanie et al., 2025). Endometriosis-related symptoms can impair physical functioning, emotional wellbeing, social relationships, sexual wellbeing, identity, professional performance or educational participation (Aerts et al., 2018; Della Corte et al., 2020; Noditi et al., 2025; Tewhaiti-Smith et al., 2022). Therefore, endometriosis-related persistent pain is not only a clinical problem, but also a condition that can affect how women live, work, relate to others, and understand themselves.

Kalfas et al. (2022), in their systematic review of psychosocial factors associated with pain and health-related quality of life in endometriosis, found that anxiety and catastrophising were the factors most consistently associated with greater pain, while anxiety, depression, and stress were associated with poorer health-related quality of life. Furthermore, women with endometriosis reported significantly lower health-related quality of life and poorer body image than controls, with somatic concern and lack of body familiarity associated with poorer health-related quality-of-life outcomes (van Niekerk et al., 2022a).

These findings further support the close relationship between symptom experience, psychological wellbeing, body-related distress, and internal burden, as well as the relevance of psychological and emotional processes in endometriosis-related pain. Importantly, they should not be interpreted as suggesting that pain is psychologically caused. Rather, they indicate that pain and distress are closely interconnected, and that emotional and cognitive processes may influence how persistent pain is experienced, managed, and endured. Much of this literature, however, is cross-sectional and focuses more strongly on psychological variables than on the social, relational, cultural, and healthcare contexts in which pain is lived. This limits what can be concluded about how these dimensions interact over time in people's everyday experiences.

Aerts et al. (2018) found that the internal burden of endometriosis-related pain is also reflected in experiences of loss of control, hopelessness, worthlessness, altered body image, and alexithymia. These experiences show that persistent pain may affect not only what people can do, but how they relate to their bodies and sense of self. They further argue that physical, mental, sexual, and social health are strongly interrelated in endometriosis. This is important because it challenges attempts to separate pain from emotional wellbeing, relationships, sexual functioning, or everyday participation.

Although psychological factors have received increasing attention, understandings of the social dimensions of endometriosis-related pain remain comparatively underdeveloped. Limited research on social factors creates a gap in understanding how social support, stigma, relationships, healthcare interactions, and broader systems shape pain and quality of life (Kalfas et al., 2022). This gap is especially relevant to the present

study, which examines pain not only as an individual experience but also as something shaped by social recognition, invisibility, support, and healthcare encounters.

Rather than cataloguing every potential impact of endometriosis, this section demonstrates that existing literature recognises endometriosis as a condition with extensive psychosocial consequences. The present study extends this literature by examining how these consequences are experienced, interpreted, and negotiated by women in Aotearoa New Zealand, with particular attention to legitimacy, care pathways, social management, internal distress, and support.

Pain Questioned: Normalisation, Dismissal, Legitimacy, and Gendered Credibility

One of the most significant psychosocial dimensions of endometriosis-related persistent pain is the difficulty of having pain recognised as abnormal, credible, and worthy of care. People with endometriosis often experience stigma, invalidation, dismissal, and normalisation of pain within healthcare and wider social contexts (Kalfas et al., 2022; Pickup et al., 2025; Sims et al., 2021). These experiences matter because they not only delay diagnosis or treatment but also shape how people interpret their own pain.

Kalfas et al. (2022) note that pain invalidation may increase shame and depressive symptoms, while Pickup et al. (2025) identify invalidation as a key factor shaping endometriosis-related pain, distress, and healthcare distrust. This suggests that external dismissal may become internal self-doubt. When pain is repeatedly framed as normal, exaggerated, anxiety-related, or not severe enough to warrant investigation, people may

begin to question whether their pain is legitimate. In this way, dismissal operates not only as a healthcare barrier but as a psychosocial process that can affect self-trust.

In Aotearoa New Zealand specifically, dismissal is a central feature of endometriosis patient experience and informs what patients prioritise in care. When symptoms were classified as ‘normal,’ dismissal could instil doubt and make it more difficult for patients to continue seeking diagnosis and treatment (Ellis et al., 2023). Dismissal, normalisation, and the need for self-advocacy recur across New Zealand patient accounts (Ellis & Wood, 2025). Together, this literature suggests that patients may need to seek information independently, advocate for investigation or treatment, and actively fight to be believed while maintaining confidence in their own bodily knowledge.

The normalisation of symptoms is also shaped by menstrual knowledge, family context, and cultural silence. Ellis, Tewhaiti-Smith, et al. (2024), in their study of Māori and Pasifika mate kirikōpū/endometriosis patients, provide important support for the role of menstrual silence, shame, and culturally shaped barriers to care. Participants described strong feelings that symptoms were normal, with some indicating that every wahine (woman) was expected to suffer in silence. Others described keeping pain to themselves, feeling like a hypochondriac, or experiencing whakamā (shame) around symptoms. This literature highlights the importance of cultural context in Aotearoa New Zealand, but it also requires careful interpretation. The present study draws on this work to situate endometriosis within local contexts of menstrual knowledge, shame, and healthcare access, without claiming to provide a comprehensive analysis of Māori and Pasifika experiences.

These experiences can be understood through wider feminist health and gendered pain literature. Research on gender bias in pain care suggests that women's pain may be underestimated, psychologised, or interpreted through assumptions about emotionality, exaggeration, coping, and women's supposed familiarity with pain through menstruation and reproduction (Samulowitz et al., 2018). In the context of endometriosis, this is particularly significant because pain associated with menstruation, reproductive organs, bowel or bladder symptoms, sex, and other embodied sites may be treated as expected, private, or difficult to legitimise rather than recognised as abnormal or requiring investigation. De C Williams et al. (2026) describe "the burden of being female" as part of endometriosis pain experience, highlighting how gendered expectations, reproductive norms, and assumptions about women's bodies can shape how pain is interpreted and legitimised.

Feminist health perspectives also help frame dismissal as a credibility issue. Carel and Kidd's (2014) concept of epistemic injustice in healthcare highlights how patients' testimony about illness may be treated as less credible or reliable because of unequal relations of knowledge and authority between patients and healthcare professionals. In this context, patients may know that something is wrong in their bodies, but their accounts may be discounted when they do not fit expected clinical evidence, diagnostic categories, or assumptions about how illness should appear. This is relevant to endometriosis because pain is often invisible, difficult to verify through routine tests, and historically normalised as menstrual suffering. Hallström (2024) similarly conceptualises an endometriosis diagnosis as a struggle for recognition, showing how dismissal, disbelief,

and misrecognition can undermine patients' confidence in their own knowledge of their bodies. These perspectives help explain why patients may not only encounter dismissal from others but may also internalise doubt about whether their pain is legitimate. Although this literature establishes that normalisation, dismissal, stigma, and credibility are important, further qualitative work is needed to understand how these processes are internalised and negotiated across everyday life, family contexts, healthcare encounters, and self-understanding.

Together, this literature suggests that pain legitimacy is socially produced. Pain must be recognised as abnormal, credible, and deserving of care. However, people with endometriosis frequently encounter barriers to recognition, including normalisation, dismissal, stigma, suspicion, and gendered assumptions about pain. Feminist health perspectives help explain why endometriosis-related pain may be particularly vulnerable to minimisation when it is associated with menstruation, reproductive bodies, invisibility, and gendered assumptions about pain.

Pain Prolonged: Diagnostic Delay, Access, Uncertainty, and Cost in Aotearoa New Zealand

Endometriosis diagnosis is often delayed internationally. As-Sanie et al. (2025) report diagnostic delays of five to 12 years from symptom onset to diagnosis, with most patients evaluated by at least three clinicians before receiving a diagnosis. While such figures provide important context, delay should not be understood only as a numerical gap between symptom onset and diagnosis. For people living with persistent pain, diagnostic

delay represents years of uncertainty, repeated help-seeking, ongoing symptoms, and often the need to justify pain to others.

In Aotearoa New Zealand, Tewhaiti-Smith et al. (2022) found that chronic pelvic pain symptoms, irrespective of final diagnosis, often began before age 20, while the mean diagnostic delay for endometriosis was 8.7 years. Participants saw an average of five doctors before diagnosis, while chronic pelvic pain negatively affected multiple life domains, including employment, education, and relationships. These findings show that diagnostic delay occurs during formative periods of life, including adolescence, education, early employment, and relationship development. Delay therefore shapes not only healthcare trajectories but also social and developmental experiences.

Menstrual literacy and early symptom recognition are also important in understanding diagnostic delay. If severe menstrual symptoms and early endometriosis-related pain are normalised within schools, families, peer groups, or wider cultural contexts, young people may not recognise their symptoms as requiring medical attention. In Aotearoa New Zealand, Bush et al. (2017) suggest that school-based endometriosis education may improve awareness and earlier recognition of symptoms. This is relevant because diagnostic delay may begin before a person enters the healthcare system: if pain is understood as normal, expected, or simply part of menstruation, help-seeking may be postponed.

More recent Aotearoa New Zealand research similarly indicates the importance of menstruation education, endometriosis awareness, and reducing taboos around

menstrual symptoms. Low awareness of endometriosis at symptom onset was associated with a two-year increase in diagnostic delay, and patients expressed wanting resources that explained the full range of endometriosis symptoms to support earlier recognition and diagnosis (Ellis et al., 2026). Menstrual literacy, therefore, provides an important bridge between the normalisation of pain and subsequent delays in diagnosis and treatment.

Recent research from Aotearoa New Zealand suggests that diagnostic delay remains substantial, although estimates vary depending on sample, diagnostic confirmation, and how delay is defined. Ellis and Wood (2024), in a study of 1024 self-reported confirmed endometriosis patients in New Zealand, reported an average diagnostic delay of 9.7 ± 7.1 years. Ellis, Tewhaiti-Smith, et al. (2024) reported average delays from symptom onset to confirmed or suspected diagnosis of 11.6 ± 7.8 years for Māori participants and 12.4 ± 6.2 years for Pasifika participants. These studies should not be read as a direct statistical comparison between ethnic groups, but they indicate that diagnostic delay is substantial across these cohorts and should be considered alongside access, cultural safety, trust in healthcare, and broader inequities.

Access to effective, timely, and supportive care is also a central issue. New Zealand patients experience long diagnostic delays, shortcomings in diagnostic tools, pain-related disruptions to work and education, and limited treatment options (Ellis et al., 2022). These issues suggest that access involves more than reaching a diagnosis; it also includes whether patients receive clear information, appropriate referrals, follow-up, symptom management, and treatment options that address the ongoing impact of pain. Māori and

Pasifika participants reported dissatisfaction with treatment availability and that poor experiences with healthcare may discourage future help-seeking (Ellis, Tewhaiti-Smith, et al., 2024). Ethnicity-based variation in referral and surgical waitlisting pathways for endometriosis and persistent pelvic pain in Aotearoa New Zealand is evident, suggesting the need for a nationally consistent and equity-focused approach to management (Dunning et al., 2025). Taken together, this literature indicates that healthcare encounters can have cumulative effects, shaping not only diagnosis and treatment but also trust, willingness to seek care, and confidence that pain will be taken seriously.

Additionally, primary care is important in the New Zealand context because general practitioners often function as the first point of contact and as gatekeepers to specialist referral. Research on New Zealand general practitioners' perspectives suggests that diagnosis and management may be affected by diagnostic uncertainty, GP knowledge and confidence, uptake of national guidance, and referral pathways (Ellis, Meador et al., 2024).

The importance of primary care is also reflected in the New Zealand guidance on diagnosis and management of endometriosis, which aims to improve early recognition of symptoms suspicious of endometriosis, empower primary care practitioners to make suspected diagnoses and begin management, support a multidisciplinary workforce, and improve equity of access and outcomes (Ministry of Health, 2020). This highlights that diagnostic delay is not only the result of individual help-seeking, but is also shaped by the structure of primary care, specialist referral processes, and the availability of timely specialist support.

The economic burden of endometriosis and chronic pelvic pain in New Zealand has also been documented. Tewhaiti-Smith et al. (2025) provide the first nationwide cost-of-illness estimate for endometriosis and chronic pelvic pain in Aotearoa New Zealand, incorporating direct healthcare, productivity, and carer costs. Their analysis identifies productivity losses as the primary cost driver and argues that diagnostic delays, poor healthcare access, and suboptimal symptom management are likely to be key modifiable contributors to this burden. This supports the view that delayed diagnosis and limited access to care have consequences beyond clinical symptoms, extending into work, finances, family life, and wider social participation. While this literature documents diagnostic delay, cost, and access barriers, survey and health-system data cannot fully show how waiting is experienced emotionally, socially, and practically by people living with ongoing pain. Qualitative research is therefore needed to understand how delay and access shape uncertainty, agency, trust, and daily life.

This literature demonstrates that diagnostic delay, access to treatment, and cost are not solely practical healthcare issues. These factors influence the duration of pain, the uncertainty surrounding symptoms, the need for repeated self-advocacy, and the financial and emotional burden of care. Waiting is an active process that involves living with pain, negotiating credibility, managing daily life, and seeking recognition and relief. This section therefore establishes the foundation for understanding 'waiting in pain' as a psychosocial experience.

Pain Socially Managed: Invisibility, Unpredictability, Work, Relationships, and Disclosure

Endometriosis-related persistent pain is not only privately endured; it must also be managed in social contexts. Pain and symptoms may be persistent, cyclical, or unpredictable, and may vary both between individuals and within the same person over time (de C Williams & McGrigor, 2024). This unpredictability can make ordinary planning difficult. Work, study, social events, relationships, and daily responsibilities may all need to be organised around symptoms that are not always visible or easily explained to others.

The difficulty of communicating pain intensifies the social burden of endometriosis. Women may find it difficult to communicate their pain and other symptoms, or to find others who can understand their struggle (de C Williams & McGrigor, 2024). This can contribute to isolation and distress, particularly when pain is minimised or misunderstood. At the same time, endometriosis pain affects daily activities, social life, employment, relationships, and emotional wellbeing (de C Williams et al., 2026). Pain may therefore limit participation not only because of physical symptoms, but because of the ongoing need to explain, justify, hide, or manage those symptoms around others.

Disclosure is a key part of this social management. Aerts et al. (2018) note that women may avoid informing employers about their diagnosis or symptoms because of possible consequences and because endometriosis is a private and gender-specific condition. This is important because endometriosis symptoms often involve menstruation, pelvic pain, bowel or bladder symptoms, fatigue, and sexual pain, all of which may be

difficult to discuss in workplaces or social settings. The private and gendered nature of the condition can therefore make support harder to access, even when symptoms are significantly affecting functioning.

Stigma further shapes whether and how pain is disclosed. Sims et al. (2021) identify several forms of stigma experienced by women with endometriosis. Enacted stigma refers to unfair, discriminatory, or dismissive treatment by others, while felt stigma refers to anticipated shame, judgement, or disbelief that may prevent people from disclosing symptoms or seeking support. Felt stigma may also contribute to self-stigmatisation, where social prejudices or stereotypes become incorporated into a person's own beliefs about themselves. This framework is useful because it explains why people may minimise symptoms, hide pain, or avoid seeking support even when symptoms are significantly affecting daily life.

This connects with de C Williams and McGrigor's (2024) distinction between self-regulation and social regulation of pain. Self-regulation may include hiding symptoms, using analgesics, careful planning, pacing, and building knowledge of the condition, while social regulation involves navigating scepticism, support, and the response of others. These processes show that living with endometriosis-related persistent pain requires ongoing social and practical work. In this way, disclosure is not a simple choice between telling and not telling; it is shaped by anticipated judgement, the gendered privacy of symptoms, workplace expectations, and previous experiences of being believed or dismissed.

The invisibility of pain also means that people may need to perform normality. Because symptoms are often not visible to others, women may appear well while internally managing severe pain, fatigue, uncertainty, or fear of symptom flares. This can create a gap between public appearance and private experience. Over time, such performance may protect against stigma or misunderstanding, but it may also intensify exhaustion, isolation, and the sense that pain is not recognised (de C Williams & McGrigor, 2024; Sims et al., 2021).

This section demonstrates that persistent endometriosis-related pain imposes significant social demands. Its unpredictability, invisibility, and gendered privacy necessitate ongoing management across work, study, relationships, disclosure, stigma, and expectations of normal functioning. This discussion informs the study's focus on how women organise their lives around pain and navigate the tension between appearing well and living with a disruptive, often invisible condition.

Pain Internally Carried: Distress, Self-Doubt, Rumination, Identity, and Self-Compassion

The literature reviewed so far demonstrates that endometriosis-related persistent pain is shaped by biological complexity, diagnostic delay, healthcare access, social recognition, and the need to manage symptoms in everyday life. These external and relational dimensions also have internal consequences. Psychological distress in endometriosis should therefore not be understood only as a separate comorbidity, but as part of living with persistent, uncertain, invalidated, and disruptive pain.

Women's accounts of painful endometriosis commonly include anxiety, depression, self-doubt, and a general sense of being unable to function adequately (de C Williams & McGrigor, 2024). Pain in endometriosis has also been associated with increased depression and anxiety, while depression, anxiety, and stress have been linked with poorer health-related quality of life (Kalfas et al., 2022). These findings suggest that psychological distress is closely connected to the ongoing experience of pain and its impact on daily life.

Qualitative research further shows that endometriosis-related pain may involve emotional, social, and identity-related disruption, including loneliness, powerlessness, uncertainty, and difficulty understanding what is happening in the body (de C Williams et al., 2026; de C Williams & McGrigor, 2024). In this way, distress is not simply an individual emotional reaction, but is shaped by the wider conditions in which pain is experienced, interpreted, and responded to.

This internal burden is also connected to uncertainty and disruption to identity. Painful endometriosis has been described as affecting women's sense of self, freedom, imagined future, and relationship with their bodies (de C Williams & McGrigor, 2024). Furthermore, women sought psychological therapy not only for pain, but also for trauma, grief, anxiety, depression, uncertainty, loss of identity and ability, and adjustment to chronic illness (Dowding et al., 2024). This indicates that endometriosis-related persistent pain can require psychological adjustment to a changed body, altered expectations, and a life that may need to be continually reorganised around symptoms.

Moreover, cognitive and meaning-making processes are relevant to the internal experience of pain. Kalfas et al. (2022) found that rumination, alexithymia, and beliefs about internal control of pain were associated with greater pain in endometriosis. Their review also found that illness acceptance and self-efficacy were associated with improved health-related quality of life. These findings suggest that the way pain is interpreted, managed, and made sense of may influence well-being. However, these processes should not be understood as purely individual psychological traits. In the context of endometriosis, rumination, self-doubt, and reduced control may be shaped by repeated dismissal, uncertain treatment outcomes, diagnostic delay, and the unpredictability of pain itself.

Åkerblom et al. (2026) also support the relevance of these processes through a biopsychosocial perspective. In a network analysis of individuals attending a tertiary endometriosis clinic, they identified perceived control and powerlessness, social support, and depression as particularly important variables within the symptom network. Psychological inflexibility emerged as the most important psychological process variable, suggesting that difficulty adapting to pain and continuing valued activities in the presence of distress may be relevant to functioning. This aligns with broader persistent pain literature while also supporting the need to understand endometriosis-related pain in context, rather than reducing it to either biological pathology or individual coping style.

Self-compassion has also emerged as a potentially important process in endometriosis. Decreased self-compassion was associated with increased psychological distress, longer diagnostic delay, greater overall symptom burden, and variation in

endometriosis-related symptom profile (van Niekerk et al., 2022b). Self-compassion was described as a possible protective resource, with higher baseline self-compassion associated with less psychological and health-related quality-of-life impairment and predicting improvements in depression over six months (Skinner & Kuijer, 2025).

These findings are important because women with endometriosis may internalise blame, doubt, or frustration toward their bodies, particularly when pain is dismissed or when they are unable to meet expected roles at work, in relationships, or in daily life. Self-compassion may therefore support a more adaptive relationship with the self and body, especially when pain remains ongoing.

Overall, the literature indicates that endometriosis-related persistent pain is internally carried through emotional distress, self-doubt, rumination, identity disruption, reduced control, and efforts to develop acceptance and self-compassion. These internal experiences are interconnected with the social and healthcare contexts reviewed earlier. They are shaped by the persistence of pain, uncertainty, invisibility, and repeated struggles for recognition. The present study therefore examines not only whether women experience distress, but how this distress is lived, interpreted, and negotiated within the broader psychosocial experience of endometriosis-related persistent pain.

Pain Made More Liveable: Support, Psychological Care, Agency, and Whole-Person Care

Although endometriosis-related persistent pain may not be cured or fully resolved, the literature suggests that support, validation, psychological care, pain relief, and

multidisciplinary approaches can help make pain more liveable. This distinction is important. Making pain liveable does not mean minimising the severity of symptoms or shifting responsibility onto individuals to cope better. Rather, it recognises that people living with persistent pain may benefit from care that addresses emotional, social, relational, and functional needs alongside medical treatment.

Dowding et al. (2024) provide important evidence on the role of psychological care in endometriosis pain management. In their mixed-methods study, women sought psychological support to adjust to and live with endometriosis. Therapy was described as helping women develop tools to get through day-to-day life, come to terms with diagnosis, and cope with the reality of living with a chronic condition. This is supported by systematic review and meta-analytic evidence suggesting that psychological interventions may improve pain, quality of life, and mental health outcomes in women with endometriosis, although the certainty of evidence is limited by risk of bias in the included studies (del Pino-Sedeño et al., 2024). This is significant because it frames psychological therapy not as a response to imagined pain, but as support for living with the emotional, practical, and identity-related consequences of persistent pain.

The types of support women found helpful also indicate the importance of validation and individualised care. Dowding et al. (2024) reported that women valued psychological tools including mindfulness, breathing and grounding techniques, cognitive behavioural therapy, acceptance and commitment therapy, self-compassion, acceptance, and strategies for managing anxiety and pain. Importantly, participants valued clinicians who provided validation, supportive and open discussion, and recognition that the pain

was real. This directly connects psychological care to the broader issue of legitimacy. For people whose pain has been dismissed, validation itself may be a meaningful component of care.

Psychological care may also be most useful when it is integrated into broader multidisciplinary support. Psychological therapy should acknowledge the chronicity and impact of symptoms and enlist multidisciplinary support (Dowding et al., 2024). Aerts et al. (2018) similarly argue that interventions should address the multidimensional nature of endometriosis. They recommend an individualised biopsychosocial approach involving multidisciplinary teams, including gynaecologists, psychologists or psychotherapists, sexologists, and physiotherapists. Although the couple-centred aspect of their model may be more relevant for studies focused on sexual or partner relationships, their broader point supports the need for care that addresses the physical, psychological, sexual, and social dimensions of endometriosis.

The COMPASS model proposed by Pickup et al. (2025), mentioned earlier in this chapter, also supports this whole-person approach. The model foregrounds agency, sense-making, systemic factors, validation, health literacy, accessible care, and multidisciplinary management. This is particularly relevant to endometriosis-related persistent pain because people may need to navigate uncertain diagnoses, limited treatment options, recurring symptoms, and fragmented care. Pickup et al.'s call to address invalidation within healthcare systems also highlights that support is not only an individual-level issue. Their findings suggest that care may be strengthened by improving

validation, health literacy, accessible treatment options, and multidisciplinary management.

Broader chronic pain and multidisciplinary care literature also supports this direction. Kovačević et al. (2024) argue that chronic pain should be approached through a biopsychosocial model within a multidisciplinary treatment framework. Fang et al. (2024) similarly support the role of multidisciplinary care in endometriosis and pelvic pain, describing the need for long-term, comprehensive, and patient-centred care delivered in a coordinated and systematic way. They also note the importance of reliable information, validation, long-term treatment planning, and social and emotional support from partners, family members, and support groups. However, Fang et al. also note that evidence for multidisciplinary care remains limited, with no fully validated framework for multidisciplinary team care in this setting. These sources position endometriosis-related persistent pain within wider developments in chronic pain and multidisciplinary care, while the thesis remains grounded in endometriosis-specific literature.

This section shifts the focus of care from cure alone to liveability, agency, and whole-person support. While pain relief remains important, it is not the sole indicator of meaningful care. Support may also include being believed, receiving clear explanations, accessing psychological therapy, developing practical coping strategies, maintaining social participation, and obtaining coordinated multidisciplinary care. For the present study, this literature contextualises participants' accounts of what helped make pain more liveable, including validation, social support, pain management, mental health care, and individualised treatment.

Chapter Summary

This chapter has reviewed literature relevant to understanding endometriosis-related persistent pain as an embodied, psychosocial, socially situated, and healthcare-mediated experience. The literature demonstrates that endometriosis-related persistent pain is clinically complex and cannot be understood through lesion-focused explanations alone. Pain may involve nociceptive, neuropathic, and nociplastic mechanisms, and may persist or recur even when lesions are treated. This supports the use of a biopsychosocial framework that recognises the interaction between biological, psychological, social, and healthcare-related dimensions of pain.

The literature also shows that endometriosis-related persistent pain has extensive psychosocial consequences. It is associated with reduced health-related quality of life, emotional distress, social disruption, impacts on work and study, relationship difficulties, and altered relationships with the body and self. Psychological processes such as anxiety, depression, catastrophising, rumination, control, acceptance, and self-compassion are relevant to the experience of pain and wellbeing. However, these processes cannot be separated from the contexts in which pain is lived, including social expectations, healthcare encounters, diagnostic delay, and access to support.

A central theme across the literature is that endometriosis pain is often questioned before it is recognised. Research from Aotearoa New Zealand and internationally shows that people with endometriosis frequently encounter normalisation, dismissal, invalidation, stigma, and delayed diagnosis. Feminist health perspectives and concepts

such as epistemic injustice help situate these experiences within broader gendered assumptions about pain, credibility, reproductive bodies, and medical authority.

The Aotearoa New Zealand literature further demonstrates that diagnostic delay, access to treatment, cost, cultural safety, and trust in healthcare are important aspects of the local context. Existing studies have identified substantial diagnostic delays, repeated healthcare encounters, access barriers, economic burden, and the need for culturally safe care. Overall, this literature provides the foundation for identifying the research problem, gap, aim, objectives, and research questions that guide the present study.

Research Gap

Existing research has established that endometriosis can have substantial physical, emotional, social, relational, and economic impacts. Research has also identified diagnostic delay, pain normalisation, healthcare dismissal, reduced quality of life, and the need for improved models of care as important issues in endometriosis. However, less attention has been given to how these dimensions come together in the lived experience of endometriosis-related persistent pain, particularly within Aotearoa New Zealand.

A further gap concerns the psychosocial meaning of persistent pain. Much endometriosis research focuses on diagnosis, symptom burden, treatment, fertility, or quality of life. While these areas are important, they do not always show how people make sense of persistent pain over time, how they manage doubt or uncertainty, how social and healthcare responses shape self-understanding, or how support and care make pain more

liveable. Persistent pain is therefore not only a clinical issue, but also an embodied, relational, emotional, and social experience that requires qualitative exploration.

There is also a need for research that attends to the interaction between individual experience and healthcare context. In Aotearoa New Zealand, endometriosis-related pain is shaped by primary care pathways, public and private healthcare access, diagnostic delay, cultural and social expectations, and uneven access to support. These conditions can affect whether pain is recognised, how long people wait, how much agency they feel, and what forms of care are available. Qualitative research can help illuminate these processes by centring the voices of those living with persistent pain.

This study addresses these gaps by exploring the psychosocial factors, dynamics, and processes that shape the lived experience of endometriosis-related persistent pain among women in Aotearoa New Zealand. It focuses specifically on how participants understood, managed, and made sense of pain across emotional, cognitive, social, interpersonal, and healthcare-related contexts. In doing so, the study contributes to a more whole-person understanding of persistent pain and highlights the importance of recognition, validation, support, and care pathways in shaping how pain is lived.

Research Problem and Rationale

Although endometriosis is increasingly recognised as a condition that can significantly affect quality of life, the psychosocial dimensions of endometriosis-related persistent pain require further attention. Persistent pain can continue to shape people's lives even after diagnosis, treatment, or surgery. For some, pain remains difficult to

explain, difficult to manage, and difficult to have recognised by others. This creates a research problem that extends beyond symptom presence alone: how do people live with, interpret, and manage persistent pain when it affects their bodies, relationships, identities, healthcare experiences, and everyday lives?

A narrow focus on diagnosis or biomedical treatment can miss important aspects of this experience. Diagnosis may validate pain, but it does not necessarily resolve the social, emotional, or practical effects of living with persistent pain. Similarly, treatment may reduce symptoms for some people, but others continue to experience pain, uncertainty, fatigue, distress, or functional limitation. Understanding endometriosis-related persistent pain therefore requires attention to the broader contexts in which pain is lived, including social recognition, healthcare access, support, stigma, emotional wellbeing, and meaning-making.

This study was also shaped by the recognition that pain is not experienced in isolation from systems of care. Healthcare encounters can either reduce or intensify the burden of pain. Experiences of dismissal, delayed diagnosis, fragmented communication, long waits, financial barriers, or lack of appropriate support can affect how people understand their pain and how much agency they feel they have. Conversely, validation, clear information, timely care, pain relief, psychological support, and multidisciplinary approaches may help make pain more liveable.

The rationale for this study is therefore to contribute a qualitative, psychosocial understanding of endometriosis-related persistent pain in Aotearoa New Zealand. By

centring participants' accounts, the study aims to illuminate how persistent pain is shaped not only by bodily symptoms, but also by recognition, relationships, healthcare pathways, emotional distress, self-understanding, and support. This rationale follows from the literature reviewed above and leads to the research gap, aim, objectives, and questions outlined below.

Research Aim, Questions, and Objectives

This research aims to explore the psychosocial factors, dynamics, and processes that shape the lived experience of endometriosis-related persistent pain. In particular, it examines how emotional distress, cognitive and meaning-making processes, interpersonal relationships, social recognition, support, and healthcare experiences influence how pain is understood, managed, and lived with. The focus on persistent pain is deliberate; the study did not seek to represent all possible experiences of endometriosis.

The research questions guiding this study are:

1. How do people with endometriosis describe the emotional and psychological impact of persistent pain?
2. How do cognitive and meaning-making processes, including self-doubt, rumination, acceptance, and self-compassion, shape how people interpret and manage pain?
3. How do social relationships, support, stigma, and interpersonal responses influence experiences of pain, coping, and wellbeing?

4. How do healthcare experiences, including recognition, access, delays, and models of care, shape the lived experience of endometriosis-related persistent pain?
5. How do these psychological, cognitive, social, and healthcare-related dimensions interact to shape the overall experience of endometriosis-related persistent pain?

The objectives of this research are:

1. To explore how emotional distress and mental wellbeing shape people's experiences of endometriosis-related persistent pain.
2. To examine how cognitive and meaning-making processes influence people's interpretations, management, and acceptance of pain.
3. To investigate how social support, interpersonal relationships, stigma, and validation influence the lived experience of endometriosis-related persistent pain.
4. To examine how healthcare encounters, access to care, diagnostic experiences, and system-level barriers shape participants' experiences of pain and pain management.
5. To understand how these psychological, cognitive, social, and healthcare-related dimensions interact within a biopsychosocial understanding of endometriosis-related persistent pain.

Chapter Three: Methodology

This chapter outlines the methodological approach used to explore the psychosocial dimensions of endometriosis-related persistent pain. As an insider researcher, I approached this study with lived experience of endometriosis and persistent pain. This positioning shaped the sensitivity I brought to the topic, the rapport developed with participants, and the need for ongoing reflexivity throughout data collection and analysis. My positionality is therefore discussed at the beginning of this chapter, before the broader methodological design is outlined.

The chapter then details the qualitative research design, recruitment process, participant characteristics, ethical considerations, data collection through semi-structured interviews, reflexive thematic analysis, and strategies used to support methodological integrity. A qualitative design was selected to prioritise understanding lived experience, meaning-making, and context, rather than measuring symptom severity or testing predetermined hypotheses (Creswell & Poth, 2018; Levitt et al., 2018). This overview introduces the methodological approach; the rationale for each methodological decision is discussed in the sections that follow.

Researcher Positionality and Reflexivity

Reflexivity was central to this study due to the close connection between the research topic and my lived experience. In qualitative research, researchers do not stand outside the production of knowledge; their positions, assumptions, relationships, and analytic decisions shape how research is conducted and interpreted (Braun & Clarke,

2022; Finlay, 2002). Reflexivity was therefore used to make my role in the research process visible, rather than to claim neutrality or detachment.

My own life has involved movement across several national and cultural contexts. I was born in South Africa, lived in China for five years, and now live in Aotearoa New Zealand. Across these contexts, I have occupied shifting positions of privilege and marginality. These experiences have shaped my concern with social justice, gendered inequality, healthcare access, and the ways power operates within institutions. This is relevant to the present study because participants' accounts often involved questions of recognition, access, legitimacy, and unequal power within healthcare and social systems.

My positioning was particularly significant because I am an insider researcher. Like the participants, I live with endometriosis and persistent pain, and have encountered issues explored in this study, such as dismissal, isolation, uncertainty, and the emotional burden of managing an often-invisible illness. I disclosed my insider status during recruitment, which appeared to facilitate rapport with many participants. Several participants spoke openly about experiences of pain, dismissal, and vulnerability, and some indicated that it was meaningful to speak with someone who understood endometriosis-related pain through lived experience rather than exclusively through clinical or academic knowledge.

However, insider status also required careful reflexive attention. Because I related strongly to many participants' accounts, there was a risk of assuming shared experience or of interpreting their stories too closely through my own lens. At the beginning of the

research, I expected many participants to describe experiences similar to mine, particularly in relation to dismissal, pain, and emotional distress. While these experiences were evident in the dataset, participants' accounts also highlighted important differences in diagnosis, healthcare access, cultural context, support, treatment, financial resources, and coping strategies. Reflexivity therefore involved attending not only to moments of recognition but also to moments in which participants' experiences differed from my own or problematised my expectations.

The interviews were often emotionally intense, as participants recounted challenging experiences and moments of vulnerability. At times, I was concerned about being either too engaged or too emotionally involved. These concerns were significant because the interviews required balancing empathy with appropriate boundaries. My aim was for participants to feel heard and understood while I maintained my responsibilities as a researcher.

I began reflexive journaling after the early interviews, recording what I felt had gone well, what I wanted to improve, what I had forgotten to ask, and what key topics appeared to be emerging. However, I did not sustain formal journaling after every interview. This was partly due to the volume of interview and transcription work, and partly due to the emotional labour involved in holding space for participants' accounts while processing my own responses. Rather than presenting reflexive journaling as a systematic procedure maintained consistently throughout the project, I understand it as one part of a broader reflexive process that also included memo-writing, supervision, repeated engagement with transcripts, and careful attention to my emotional and interpretive responses.

Transcription also supported reflexive engagement with the data. Listening closely to each interview allowed me to revisit participants' words, pauses, emotions, and emphases, while also noticing my own responses to their accounts. At times, this process brought up strong feelings, particularly when participants described medical bias, gendered dismissal, or the difficulty of being ill while not appearing visibly unwell. These responses did not make the research less valid; rather, they reinforced the need to approach analysis carefully, transparently, and reflexively.

Prior to coding and analysis, I engaged with Braun & Clarke's (2022) *Thematic Analysis: A Practical Guide* and completed several reflexive exercises. These exercises helped me consider how my social location, assumptions, insider status, and emotional investments might influence the questions I asked, the patterns I noticed, and the interpretations I developed.

Throughout the study, I did not aim to be an objective or detached observer. My experiences shaped the questions I asked, the sensitivity I brought to interviews, and the patterns I noticed during analysis. At the same time, I sought to remain open to the diversity and complexity of participants' accounts. Supervision, memo-writing, and repeated movement between codes, extracts, and developing themes helped me consider whether my interpretations were grounded in participants' accounts rather than simply reflecting my own experiences or assumptions.

This reflexive positioning shaped how I represented participants' stories. I approached participants as experts in their own experiences and aimed to write about

their pain in a manner that preserved both its embodied reality and its social and psychological complexity. My intention was not to speak for participants, but to interpret patterns across their accounts while honouring the specificity and dignity of their lived experiences.

Research Design and Methodological Orientation

This study used a qualitative research design to explore the psychosocial factors, dynamics, and processes that shape the lived experience of persistent pain associated with endometriosis. A qualitative approach was appropriate because the study aimed to understand how participants made sense of pain in the context of their everyday lives, relationships, healthcare encounters, emotional wellbeing, and coping attempts. Rather than measuring pain severity or testing predetermined hypotheses, the study sought to generate rich, contextualised accounts of how persistent endometriosis-related pain was understood, managed, and lived with (Creswell & Poth, 2018; Levitt et al., 2018).

The study was informed by an interpretive orientation, which recognises that people make meaning of their experiences through personal, social, cultural, and relational contexts (Creswell & Poth, 2018). This was important because endometriosis-related persistent pain was not only described as a physical sensation, but also as an experience shaped by recognition, dismissal, uncertainty, support, stigma, and access to care. Participants' accounts were therefore approached as meaningful interpretations of lived experience rather than as objective clinical records or simple descriptions of symptoms.

At the same time, the study did not treat pain as merely socially constructed. Endometriosis-related persistent pain was understood as embodied and materially consequential. Participants described pain as affecting mobility, employment, study, parenting, intimate relationships, mental wellbeing, medical decision-making, and future planning. The methodological orientation therefore needed to hold together both the physical reality of pain and the social contexts through which pain was interpreted, legitimised, questioned, or supported.

A biopsychosocial understanding of persistent pain provided the primary conceptual foundation for the study. This framework was useful because it allowed pain to be understood as shaped through interactions between biological, psychological, and social dimensions, rather than a purely biomedical problem (Gatchel et al., 2007). In this study, it supported attention to physical symptoms and treatment histories alongside emotional distress, meaning-making processes, interpersonal relationships, social support, healthcare encounters, and broader structural conditions.

The study was also sensitised by feminist health perspectives, particularly work examining how gendered assumptions about pain, medical authority, and patient credibility can shape healthcare encounters for people with endometriosis and chronic pain (Samulowitz et al., 2018; Young et al., 2020). These perspectives were relevant because many participants described having to prove, justify, or legitimise pain that others had minimised. Feminist health perspectives helped orient the research toward gendered assumptions, social expectations, and healthcare power relations, while remaining sensitising concepts rather than as a rigid framework imposed on the data.

This methodological positioning was compatible with reflexive thematic analysis. Reflexive thematic analysis recognises that themes are actively developed through the researcher's interpretive engagement with participants' accounts (Braun & Clarke, 2022). The aim was therefore not to produce a single objective account of endometriosis-related persistent pain, but to develop a coherent and reflexive interpretation of patterns of meaning across participants' accounts.

Participant Recruitment

Participants were recruited using purposive sampling. This was appropriate because the study sought to recruit people with direct lived experience of endometriosis-related persistent pain who could provide detailed accounts relevant to the research aim (Creswell & Poth, 2018; Curtis & Curtis, 2011). Recruitment occurred through healthcare settings and endometriosis community networks in Aotearoa New Zealand.

The first recruitment pathway involved contacting healthcare providers across public and private healthcare settings to request permission to display the study recruitment materials via a standardised email (Appendix A). Providers were given the ethics approval documentation and recruitment flyer (Appendix B, Figure B1) before agreeing to display the material. In some cases, healthcare providers printed and displayed the flyer themselves. In other cases, where geographically possible, I visited the healthcare space and displayed the flyer with permission. Physical flyer distribution was primarily limited to Auckland because of practical travel constraints.

The second recruitment pathway involved contacting three prominent endometriosis organisations in Aotearoa New Zealand: Insight Endometriosis, Endometriosis New Zealand, and Endo Warriors Aotearoa. These organisations were approached because of their connections with people affected by endometriosis and their role in providing information, advocacy, and support. All three organisations agreed to share the recruitment flyer or the modified social media tile (Appendix B, Figure B2) on their social media pages, and some also circulated the flyer through their wider networks. This online recruitment pathway enabled the study to reach participants beyond Auckland and was the primary source of recruitment.

Potential participants were eligible if they were over 18 years of age, living in New Zealand, able to participate in English, clinically diagnosed with endometriosis, and experiencing persistent pain related to endometriosis. Potential participants contacted me directly by email after seeing the recruitment material. This self-initiated contact helped protect voluntary participation and reduced the likelihood that individuals would feel pressured to take part.

Once a potential participant expressed interest, I emailed them the participant information sheet (Appendix C) and invited them to review it carefully. If participants responded to the information sheet and indicated they remained interested, I arranged a brief phone or Microsoft Teams call to discuss the study, confirm eligibility, explain what participation would involve, and provide an opportunity to ask questions. If participants chose to proceed at the end of the discussion, an interview time was arranged. The consent form (Appendix D) was emailed to participants and completed before the

interview date and emailed back. No interview commenced until informed consent was obtained.

Participant Characteristics

The interview data presented in this study draw on in-depth semi-structured interviews with 13 women with endometriosis-related persistent pain in Aotearoa New Zealand. Of the 13 participants, eight identified as European (61.5%), two as European/Māori (15.4%), one as Māori/Pasifika (7.7%), one as Pasifika (7.7%), and one as Asian (7.7%). Participants were located across Aotearoa New Zealand, with most participants living in Auckland (n = 7). Two participants lived in the Bay of Plenty, and the remaining participants lived in Canterbury, Nelson, Wellington, and Waikato, respectively.

The inclusion criteria did not require participants to identify as women, as endometriosis can affect people assigned female at birth across diverse gender identities. However, all 13 participants in this study identified as female and referred to themselves as women. For this reason, participants are referred to as women throughout the thesis.

At the time of interview, participants were aged 22 to 44 years, with an average age of 33.6 years. Most participants described symptom onset during adolescence, with 12 of the 13 reporting onset between the ages of 10 and 18 years. Only one participant reported symptom onset in adulthood. Age of diagnosis varied across the sample. Four participants were diagnosed before age 20 years, four were between 20 and 29 years old, three were between 30 and 39 years old, and two were 40 years or older.

Table 1 summarises key demographic and contextual characteristics of the participants in aggregated form. Participants varied in diagnostic timing, treatment histories, educational backgrounds, employment status, and time living with endometriosis-related persistent pain. These characteristics are presented descriptively to provide context for the sample. The meaning and impact of diagnostic delay, healthcare navigation, uncertainty, and ongoing pain are interpreted in Chapter Four.

Table 1

Participant Demographic and Diagnostic Characteristics

Characteristic	n	%
Age, years		
<i>M</i> = 33.6, range = 22–44		
Age group		
20–24 years	3	23.1
25–29 years	1	7.7
30–34 years	3	23.1
35–39 years	2	15.4
40–44 years	4	30.8
Gender		
Female	13	100.0
Ethnicity		
European	8	61.5
European/Māori	2	15.4

Characteristic	n	%
Māori/Pasifika	1	7.7
Pasifika	1	7.7
Asian	1	7.7
Highest level of education		
Secondary school or equivalent	2	15.4
Certificate or diploma	2	15.4
Bachelor's degree	7	53.8
Postgraduate qualification	2	15.4
Employment status		
Employed full-time	7	53.8
Employed part-time	2	15.4
Student	1	7.7
Not currently employed	3	23.1
Region		
Auckland	7	53.8
Bay of Plenty	2	15.4
Canterbury	1	7.7
Nelson	1	7.7
Wellington	1	7.7
Waikato	1	7.7
Age of diagnosis		
Under 20 years	4	30.8

Characteristic	n	%
20–29 years	4	30.8
30–39 years	3	23.1
40 years or older	2	15.4

Note. $N = 13$. Percentages are rounded to 1 decimal place and may not total 100 due to rounding.

Ethical Considerations

Ethical approval for this study was granted by the University of Waikato Human Research Ethics Committee. Given the sensitive nature of the research topic, ethical considerations focused particularly on voluntary informed consent, confidentiality, and the reduction of potential harm. No unforeseen ethical issues arose during data collection.

As outlined in the recruitment section, consent was staged rather than assumed. Potential participants were provided with a participant information sheet (Appendix C) before deciding to take part and were given the opportunity to ask questions before an interview was arranged. Participants were informed that participation was voluntary; they could decline to answer any questions, pause or stop the interview, and withdraw from the study up to two weeks after the interview. No interview commenced until informed consent had been obtained. This staged recruitment and consent process ensured that participants had time to consider the study, ask questions, and make an informed decision about participation.

Participants were invited to discuss experiences of endometriosis-related persistent pain, which had the potential to involve distressing or personal topics. The potential for distress was explicitly addressed in the participant information sheet (see Appendix C) and monitored during data collection. Although the interviews were not designed to be therapeutic, they invited participants to reflect on experiences that could be emotionally difficult. In-depth interviews can involve disclosure of sensitive information, requiring attention to participant comfort during and after the interview (Curtis & Curtis, 2011). To reduce potential harm, the interview process was flexible and participant-led. If participants showed signs of distress, they were offered the option to pause, stop the interview, or move to a different topic. A list of relevant support services and contact details was also provided in the participant information sheet.

As the interview process progressed, I incorporated a brief closing check-in from the fourth interview onward. This was used to gauge participants' feelings after the interview and to avoid ending the conversation immediately after difficult or painful material. Where appropriate, the check-in invited participants to reflect on how far they had come in their journey or on what they hoped might come from sharing their story. Many participants expressed a desire for the research to help other women with endometriosis. This closing process was not intended to minimise the difficulty of participants' experiences, but to close the interview in a way that felt respectful, containing, and emotionally safe.

Confidentiality and de-identification were also important ethical concerns. Participants were assigned participant numbers for data management and analysis, and

identifying details were removed or altered where necessary. However, participant numbers are not attached to quotations in the findings chapter. This decision was made to reduce the possibility of linking extracts across themes and to support participant confidentiality, particularly where accounts included distinctive combinations of location, healthcare providers, surgeries, employment, family relationships, cultural identity, or fertility experiences. These details could increase the risk of deductive disclosure if presented too fully. For this reason, demographic information was reported in broad categories where appropriate and Table 1 presents characteristics in aggregated form. Quotations were also selected and presented carefully to protect participants' identities while preserving the meaning of their accounts.

All data were stored securely in accordance with the conditions of ethical approval. Interview recordings, transcripts, consent forms, demographic information, and analysis documents were stored in password-protected digital files accessible only to the researcher and, where appropriate, the research supervisor. In the thesis, participants' accounts were presented through de-identified quotations and analytic interpretation.

Data Collection

Data were collected through in-depth semi-structured interviews with 13 participants. Semi-structured interviews were chosen because they allowed participants to describe their experiences in their own words while also ensuring that key areas relevant to the research questions were explored (Kvale & Brinkmann, 2015). This format was appropriate for the study because endometriosis-related persistent pain is a complex and

personal experience involving physical symptoms, emotional distress, healthcare encounters, social relationships, and processes of meaning-making.

At the beginning of each interview, participants completed a short demographic questionnaire (Appendix E) using Microsoft Forms. The questionnaire collected descriptive information, including age, gender, ethnicity, highest level of education, employment status, location, age at diagnosis, and diagnostic history. Participants were informed that questionnaire responses would be stored on secure, password-protected university servers and kept separate from identifying contact details. The demographic information was used solely to describe the participant sample and provide context for interpreting the interview data. All questionnaire items were optional.

Interviews were conducted either in person or through Microsoft Teams. Five interviews were conducted in person, four in Auckland and one in Waikato, and the remaining eight were conducted online via Microsoft Teams. Interviews ranged from 65 minutes to 113 minutes, with an average duration of approximately 79 minutes. The use of both in-person and online interviews enabled participation from women living in different regions of Aotearoa New Zealand and provided flexibility for participants managing pain, fatigue, work, study, caregiving, or other commitments.

An interview guide (Appendix F) was used to support the semi-structured format of the interviews. The guide explored psychosocial domains relevant to the research questions, including general pain experiences, mental health, cognitive processing and coping, social dimensions, and treatment and interventions. Although the guide provided a

structure, it was used flexibly. The interviews were conversational in tone, with attention given to participants' comfort and emotional safety. Participants were encouraged to focus on the areas of their experience that felt most meaningful to them, and follow-up questions were used to explore topics raised by participants in more depth. Although healthcare system experiences were not initially a primary domain in the interview guide, this topic emerged naturally from participants' accounts and was explored in later interviews.

All interviews were audio-recorded with participants' consent. No video recordings were retained. Interviews conducted through Microsoft Teams were recorded using the platform's audio recording and transcription functions. In-person interviews were also audio-recorded via Microsoft Teams so that the same transcription process could be used across the dataset. Automated transcripts generated by Microsoft Teams were checked and edited for accuracy by the researcher. During this process, identifying information was removed from transcripts to protect confidentiality and de-identification.

Recordings were deleted after transcription was completed, in accordance with the study's ethical procedures. De-identified transcripts were stored securely in password-protected files accessible only to the researcher and, where appropriate, the research supervisor. The transcription process also facilitated familiarisation with the data, as repeated listening and transcript checking enabled close engagement with participants' accounts before formal coding began.

After the first three interviews, the transcripts were shared with my supervisor for review. This was done to reflect on the interview process, consider how the interviews were unfolding, and identify areas where my questioning or facilitation could be improved. This early supervisory feedback helped refine later interviews while maintaining the same overall semi-structured approach.

Data Analysis

Data were analysed using reflexive thematic analysis, as outlined by Braun and Clarke (2022). Reflexive thematic analysis was chosen because it supports the identification and interpretation of patterns of meaning across a qualitative dataset. This approach was appropriate because the study aimed not only to describe participants' experiences of endometriosis-related persistent pain, but to interpret how pain was made meaningful through emotional, cognitive, social, and healthcare-related contexts.

The analysis followed an iterative and reflexive process. Familiarisation began during data collection and transcription, as I listened to recordings, checked automated transcripts, corrected errors, and removed identifying information. I then read and reread the transcripts to develop an overall sense of the dataset, noting initial impressions, recurring ideas, emotional responses, and potential areas of analytic interest.

Initial coding was conducted across the full dataset using Microsoft Word's commenting feature. At this stage, coding was broad and inclusive, with attention given to both explicit content and underlying meanings. Many early codes were descriptive, capturing features of participants' accounts such as diagnostic delay, dismissal, pain

flares, medication use, work disruption, social withdrawal, self-doubt, emotional distress, support, and healthcare access. These codes provided a foundation for later theme development, but they were not treated as final analytic categories.

As analysis progressed, I moved from descriptive coding toward broader patterns of meaning. Extracts and their corresponding codes were exported into Microsoft Excel, where codes were compared across participants and grouped into potential clusters. This involved asking what different codes had in common, what forms of experience they represented, and how they related to the research questions. For example, codes relating to normalisation, dismissal, negative scans, proof-seeking, and diagnostic validation were gradually brought together around the broader analytic idea of pain legitimacy. Similarly, codes relating to waiting, financial access, fragmented care, and repeated storytelling were grouped into a theme exploring how healthcare pathways shaped uncertainty, agency, and the duration of pain.

Theme development was active and interpretive. Themes were not understood as simply emerging from the data, but as being developed through sustained engagement with participants' accounts, the research questions, and reflexive notes (Braun & Clarke, 2022). A thematic map was created and revised to examine relationships between candidate themes and subthemes. This map functioned as an analytic tool rather than a fixed template, helping me consider where patterns overlapped and where clearer boundaries were needed.

Through further analysis, candidate themes were refined into more distinct themes that separated pain legitimacy, healthcare pathways, social visibility, internal psychological burden, and forms of support that made pain more liveable. Candidate themes were reviewed several times by revisiting transcripts, checking whether themes were grounded in the data, moving extracts between themes, renaming themes, and clarifying the central organising concept of each theme. This was important because, in reflexive thematic analysis, themes represent patterns of shared meaning rather than merely summarise topics discussed by participants (Braun & Clarke, 2022).

The analysis was informed by the study's biopsychosocial understanding of persistent pain and sensitised by feminist health perspectives on gendered pain, legitimacy, and dismissal. These perspectives guided attention to how pain was shaped through interactions among embodied symptoms, emotional distress, cognitive meaning-making, social relationships, and healthcare encounters. However, the analysis was not organised deductively around predetermined biopsychosocial categories. Instead, the themes were developed inductively and reflexively through engagement with the interview data while remaining informed by the broader conceptual concerns of the study. The final thematic structure is presented in Chapter Four (Table 2).

Methodological Integrity

Methodological integrity was supported through attention to coherence, transparency, reflexivity, rich data, and grounding in participants' accounts. In qualitative research, quality is not established primarily through claims of objectivity or replicability in

the same way as in quantitative research. Instead, it is supported by demonstrating that the research design, data collection, analysis, and interpretation are appropriate to the research aim and are reported clearly and transparently (Levitt et al., 2018). This approach was also consistent with qualitative health research quality principles, including sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance (Yardley, 2000).

In preparing this chapter, I was also guided by qualitative reporting standards relevant to psychology and reflexive thematic analysis. The Journal Article Reporting Standards for Qualitative Research (JARS-Qual) informed the transparent reporting of the study's design, researcher positionality, participant recruitment, data collection, analytic process, and methodological integrity (Levitt et al., 2018). Braun and Clarke's Reflexive Thematic Analysis Reporting Guidelines (RTARG) also supported the reporting of reflexive thematic analysis by encouraging clarity regarding theoretical assumptions, researcher reflexivity, coding, theme development, and the researcher's active role in interpretation (Braun & Clarke, 2024). These guidelines were not used as rigid checklists, but as tools to support clear, coherent, and reflexive reporting of the research process.

Coherence was supported by maintaining clear connections among the study aim, research questions, interview guide, analytic approach, and final themes. The interview guide explored domains relevant to the research questions, including pain experiences, mental health, cognitive processing and coping, social dimensions, and treatment and interventions. These domains provided a foundation for data collection but were not treated as fixed analytic categories. The final themes remained aligned with the study aim

by focusing on pain legitimacy, healthcare pathways, social visibility, internal psychological burden, and forms of support and care that made pain more liveable.

Transparency was supported by documenting the research process. This chapter has outlined the recruitment procedures, inclusion criteria, participant characteristics, interview procedures, transcription processes, and analytic approach. The analysis section described how initial codes were developed, clustered, reviewed, and refined into themes. The thematic map also supported analytic transparency by documenting relationships between candidate themes and subthemes.

Reflexivity contributed to methodological integrity by making visible how my insider position shaped the research process. My lived experience of endometriosis and persistent pain supported rapport and sensitivity during interviews, but also required attention to assumptions, over-identification, and the possibility of interpreting participants' accounts too closely through my own experience. Reflexive notes, supervision, and repeated movement between data extracts, codes, and themes helped me consider how my position influenced the questions I asked, the meanings I noticed, and the interpretations I developed.

The use of participant quotations in the Findings and Discussion chapter further strengthened methodological integrity by grounding analytic claims in the data. Quotations were selected to illustrate key patterns of meaning while preserving the complexity and specificity of participants' experiences. In presenting participant quotations, minor edits were made to support readability while preserving participants' intended meaning. Filler

words, repeated words, false starts, and verbal hesitations such as “like,” “just,” “you know,” or repeated phrases were occasionally removed where they did not contribute analytically to the extract. Ellipses were used to indicate where irrelevant or lengthy sections of speech had been omitted. Square brackets were used either to add brief contextual information needed for clarity or to replace identifying details, such as names of people, places, workplaces, or healthcare providers.

These edits were made carefully and conservatively, with the aim of protecting confidentiality and improving readability without changing the substance, tone, or meaning of participants’ accounts. Care was taken to avoid using quotations as substitutes for analysis. Instead, extracts were used alongside analytic commentary to show how the themes were developed and what they contributed to understanding endometriosis-related persistent pain.

Attention was given to complexity and variation within the dataset. Although shared patterns were identified across participants’ accounts, the analysis did not assume that all participants experienced pain, healthcare, support, or coping in the same way. Differences in diagnostic timing, access to care, cultural background, employment, financial resources, treatment experiences, and support networks were considered during analysis. This helped avoid presenting participants as a homogeneous group and supported a more nuanced interpretation of persistent pain as a psychosocial experience.

Sample adequacy was assessed in terms of information power, depth, and relevance rather than statistical representation or saturation. Saturation was not pursued

in this study because reflexive thematic analysis does not assume that all possible meanings can or should be exhausted, nor does it require data collection to continue until no new codes or themes are identified (Braun & Clarke, 2021, 2022). Instead, the focus was on generating data that were sufficiently rich and relevant to address the research questions and support meaningful interpretation. Information power was considered adequate when the sample was sufficiently specific for the study aim, the research questions were clearly focused, the dialogue in interviews was strong, and the analytic approach allowed for in-depth engagement with the data (Malterud et al., 2016).

Finally, transferability was supported through the provision of contextual details about the sample, recruitment pathways, data collection, and the analytical process. The findings are not intended to be statistically generalisable to all people with endometriosis. Rather, they offer rich, contextualised insight into how this group of participants in Aotearoa New Zealand experienced endometriosis-related persistent pain. By clearly describing the research context and analytic process, readers can consider the relevance of the findings to other settings, populations, or healthcare contexts.

Chapter Summary

This chapter outlined the methodological approach used to explore the psychosocial dimensions of endometriosis-related persistent pain. The study used a qualitative design informed by a biopsychosocial understanding of persistent pain and sensitised by feminist health perspectives on gendered pain, legitimacy, and healthcare dismissal. Researcher positionality and reflexivity were central to the study, particularly

given my insider position as someone with lived experience of endometriosis and persistent pain.

Participants were recruited through purposive sampling via healthcare settings, endometriosis organisations, social media, and community networks. Thirteen women with clinically diagnosed endometriosis and persistent pain took part in in-depth semi-structured interviews. The interviews were flexible and participant-led, exploring key psychosocial domains, including emotional wellbeing, cognitive and meaning-making processes, social relationships, healthcare experiences, and pain management.

Data were analysed using reflexive thematic analysis. This involved familiarisation, broad initial coding, theme development, thematic mapping, and ongoing reflexive engagement with the data. Methodological integrity was supported through transparency, coherence, reflexivity, rich participant accounts, careful ethical procedures, and attention to complexity within the dataset. Together, these methodological decisions supported the development of a nuanced qualitative account of how participants in Aotearoa New Zealand lived, interpreted, and made sense of persistent endometriosis-related pain.

Chapter Four: Findings and Discussion

This chapter presents and discusses the findings of the study through five themes, using illustrative extracts from participants' interviews. Rather than separating findings from discussion, each theme integrates participants' accounts with relevant literature to consider how the findings align with, extend, and complicate existing understandings of endometriosis-related persistent pain. This integrated structure reflects the qualitative and interpretive orientation of the study by keeping participants' meanings central while situating the analysis within wider literature on psychosocial wellbeing, healthcare experiences, social recognition, and whole-person care.

The findings are organised around five interconnected but distinct dimensions of endometriosis-related persistent pain. The first theme examines how participants struggled to have pain recognised as real, abnormal, and legitimate. The second theme considers how healthcare pathways shaped the duration, uncertainty, and emotional burden of living with pain. The third theme focuses on the social and external impacts of pain, including work, study, relationships, disclosure, and public/private functioning. The fourth theme turns inward to examine the psychological burden of pain, including grief, guilt, self-doubt, rumination, distress, and acceptance. The final theme brings the findings together by examining what made pain more liveable, including support, pain relief, mental health care, individualised and multidisciplinary care, and agency.

Table 2 provides an overview of the final thematic structure. The themes are presented as interconnected rather than linear; together, they show a movement from pain

being questioned and prolonged to pain being managed socially and carried internally, and finally to the forms of support and care that made pain more liveable.

Table 2

Final Themes and Subthemes

Theme	Subthemes
“No amount of pain should be normal”: struggling to legitimise pain	Pain made ordinary; Pain that had to look right; The burden of proof; Diagnosis as validation and fragile legitimacy
Waiting in pain: care pathways, uncertainty, and the cost of access	Access shaped agency; Paying for time, not cure; Waiting as suspended life; Fragmented care and emotional labour
Living with an unpredictable and invisible body	Pain that cannot be scheduled; “You look fine”: social invisibility and disclosure; Performing normality; Organising life around pain
Carrying pain internally: distress, self-doubt, and self-compassion	Pain and the disrupted self; Guilt, burden, and self-doubt; Rumination, mood, and psychological distress; Rebuilding through self-compassion and acceptance
Making pain liveable: support, relief, and whole-person care	Support as validation, belonging, and survival; Pain relief as participation; Mental health care as pain care; A suite of care: individualised, multidisciplinary, and agency-building

Together, these themes show that endometriosis-related persistent pain was not only a physical symptom. It was a psychosocial experience shaped by recognition, care

pathways, social life, psychological meaning, and access to support. Although the themes overlap, each addresses a different aspect of how pain was lived: pain questioned, pain prolonged, pain socially managed, pain internally carried, and pain made more liveable.

Theme 1: “No Amount of Pain Should be Normal”: Struggling to Legitimise Pain

This theme examines how participants came to understand their pain as real, abnormal, and worthy of care, and how others recognised or dismissed it. The focus of this theme is the legitimacy of pain. Participants’ accounts show that pain was often normalised as part of menstruation, dismissed when it did not appear in expected ways, psychologised as anxiety or overreaction, and made difficult to prove. As a result, participants were not only managing pain itself; they were also managing the question of whether their pain would be believed.

Across accounts, participants were repeatedly positioned as having to justify pain that they already experienced as real. Pain was difficult to legitimise when it was treated as ordinary menstrual pain, when it did not appear clearly on scans or tests, when it was not displayed in expected ways, or when participants’ attempts to seek relief were read through suspicion. This meant that pain was not only a bodily experience, but a social and psychological one. Participants had to learn to trust their own bodies while navigating messages that encouraged them to doubt, minimise, or explain away their pain. This theme therefore shows legitimacy as an ongoing psychosocial process rather than a single moment of being believed. Pain had to be recognised as abnormal by participants

themselves, made credible to others, translated into medically legible evidence, and re-legitimised when diagnosis or treatment did not resolve symptoms.

This theme is organised into four subthemes: Pain made ordinary; Pain that had to look right; The burden of proof; and Diagnosis as validation and fragile legitimacy.

Pain Made Ordinary

Participants' accounts suggest that persistent pain was often difficult to recognise because menstrual and pelvic pain had been normalised. Severe pain could be interpreted as part of becoming a woman, something to tolerate, or evidence of low pain tolerance rather than illness. This normalisation shaped the threshold at which pain became recognisable as a problem. Participants were not simply lacking information about endometriosis; they were living within social contexts where pain was expected, minimised, or made ordinary.

For some participants, the normalisation of pain was reinforced by limited menstrual and endometriosis education at school and at home. Participants described growing up without clear information about what level of menstrual pain might signal a problem, which made severe symptoms harder to recognise as abnormal. One participant reflected on the absence of this education in school:

But I think more awareness in schools would be so helpful because ... in health, we never learned anything like that when I was at school. Like, hey, if you're getting a period and these things are happening, maybe that's not normal to be in that amount of pain.

This quote highlights that pain was not only normalised through direct dismissal, but also through educational silence. Without language for endometriosis or abnormal menstrual pain, participants could struggle to interpret severe symptoms as warranting concern. In this sense, the lack of menstrual and endometriosis education helped create the conditions in which pain could be endured rather than questioned.

For some participants, family members did not have the language or knowledge to understand severe menstrual pain as a possible sign of illness. One participant described how her mother interpreted her symptoms through the only framework available to her:

Because even my mum didn't know anything about endometriosis or periods, and when I would sweat and vomit and have really bad stomach pains, my mum always thought, 'Oh my gosh, she's pregnant. She's pregnant.' 'Cause that was the only level [of] understanding she had.

This account underscores how limited knowledge shaped the meaning attached to pain. The participant's symptoms were not necessarily ignored, but they were interpreted through an available explanation that did not make endometriosis visible. Without a framework for abnormal pain, participants' experiences could remain confusing, misread, or disconnected from medical help. Pain therefore became harder to legitimise because it had not yet been made intelligible.

Another participant described how, within her Pacific Island family context, menstrual cycles were not openly discussed:

Overall, my endometriosis journey, for someone like myself who's Pacific Island, we don't really tend to discuss cycles within the family. One of the conversations my mother just told me was, 'It's what women go through, and this is what you use.' And that was it. That was my education and introduction to periods.

This account shows how menstrual silence at home could reinforce the idea that pain was simply part of womanhood. The participant's introduction to menstruation focused on managing periods rather than recognising when pain might indicate illness. This does not suggest that all Pacific families approach menstruation in the same way. Still, it highlights how cultural and familial silence can shape menstrual literacy and make pain more difficult to name as abnormal.

Taken together, these accounts show that pain normalisation was not only a matter of insufficient information, but a social process through which participants learned what kinds of menstrual pain were expected, tolerable, or worthy of concern. Existing research has shown that limited menstrual literacy, low endometriosis awareness, and symptom normalisation can contribute to delayed recognition and diagnosis (Bush et al., 2017; Ellis et al., 2023; Ellis et al., 2026). The present findings extend this literature by showing how normalisation was produced through everyday settings, including schools, families, peer groups, and gendered expectations of endurance. Participants were not only delayed by healthcare systems; they first had to interpret their own pain within social contexts that made severe symptoms seem ordinary, private, or shameful. In this sense, diagnostic delay may begin before healthcare contact, when pain is not yet intelligible as illness.

Normalisation occurred through comparison with other people's periods.

Participants described being surrounded by messages that menstrual pain was expected and that women should accept it. This could lead participants to compare themselves with others and conclude that they were weak, dramatic, or unable to cope:

And I think ... there's lots of messaging. Interestingly, I find it also comes from other women, as well as wider society, about that's just normal, and that's part of being a woman and accept that's supposed to hurt. And so I just sort of internalise it as, 'Oh, I must just not have a very high pain tolerance or something'.

This quote demonstrates how social messages about women's pain could become internalised. The participant did not initially interpret severe pain as evidence that something was wrong; she interpreted her inability to tolerate it as evidence of personal deficiency. Normalisation therefore did more than delay help-seeking. It shaped participants' self-understanding by turning pain into a question of endurance, strength, or weakness.

The normalisation of pain affected social recognition. When others understood menstrual pain only through their own experiences, they sometimes struggled to believe that participants' pain could be as severe as described. One participant recalled learning that her friends doubted her pain and surgery:

And the reason I questioned my pain was because when I was in high school, my last year when I was getting diagnosed ... I'd heard from one of my friends, it was just the two of us that day, that the others didn't believe that I'd had surgery. They

thought I was just wanting attention and that I was faking the pain because they were like, 'We get our periods, and it's not that bad.'

This reflection suggests how normalisation can become disbelief. The participant's friends used their own comparatively manageable periods as the standard against which her pain was judged. Because their pain was "not that bad," her pain became difficult to accept as real. This is significant because it shows how pain that exceeds social expectations may be interpreted not as illness, but as exaggeration. In this way, the legitimacy of pain was shaped by what others believed menstrual pain should look like.

This also connects with Hallström's (2024) discussion of comparison as part of how people come to know endometriosis. In the present study, comparison did not simply help participants recognise abnormal pain; it could also work against recognition when others' more manageable periods became the standard against which participants judged themselves. Peer comparison therefore became a route into self-doubt as well as a possible route into knowledge.

This finding also connects with feminist health literature on gendered expectations of pain. Samulowitz et al. (2018) argue that women's pain may be underestimated or interpreted through assumptions about emotionality, coping, exaggeration, or women's supposed familiarity with pain through menstruation and reproduction. In the present study, participants' pain was not always dismissed through direct disbelief; it was often made ordinary through everyday assumptions about what menstruating bodies should tolerate. This extends existing literature by showing that normalisation was not only a

barrier to diagnosis, but also a process through which participants learned to doubt the seriousness of their own pain. Pain became difficult to recognise as abnormal because it had already been positioned as something expected, private, or endured.

The consequences of normalisation were significant. Participants often realised later that symptoms they had tried to tolerate were not normal. By then, pain had often already affected education, work, relationships, emotional wellbeing, and trust in the body. Normalisation therefore shaped pain at the level of meaning. It made severe symptoms seem ordinary, something to be kept private, or shameful, and made participants question whether they were entitled to seek care.

Pain That Had to Look Right

Participants' pain was difficult to legitimise because it often did not appear in ways others expected. In clinical encounters, pain could be dismissed when scans were normal, when participants looked composed, or when their distress was interpreted as anxiety rather than evidence of pain. Participants were therefore caught in a double bind: they had to show pain convincingly enough to be believed, but not so visibly that they were pathologised, judged, or dismissed as overreacting.

One participant described the confusion of being told nothing appeared on a scan despite later being diagnosed with severe disease:

If people could realise how horrific endometriosis is. And then as well to be told there's nothing shown on your scan, which I was told. I had a scan. Pelvic scan.

Nothing on there. And I had stage 4 [endometriosis]. Everything was tied [together].

How? How can that be?

This extract demonstrates how normal imaging could become a source of invalidation. The participant's question, "How can that be?", captures the gap between embodied pain and medical visibility. Pain therefore became harder to legitimise when it could not be easily seen, measured, or explained. This also shows how medical technologies can become part of the legitimacy process. A normal scan did not remove the participant's pain, but it could make the pain harder to explain to others.

These findings align with literature showing that endometriosis-related pain can be difficult to legitimise when it is invisible, unsupported by routine tests, or inconsistent with expected clinical signs. As-Sanie et al. (2025) emphasise that pain severity does not map neatly onto visible lesions or disease features, while Ministry of Health guidance also recognises that normal imaging does not exclude endometriosis (Ministry of Health, 2020). The present findings show the psychosocial consequences of this clinical mismatch. When pain did not appear in expected ways, participants' accounts could be treated as less credible, even when symptoms were severe and disruptive. This reflects what Carel and Kidd (2014) describe as epistemic injustice in healthcare, where patients' testimony can be downgraded when it does not fit dominant forms of clinical evidence. The problem was therefore not only diagnostic uncertainty, but the expectation that pain should become visible in order to be believed.

Participants described how living with chronic pain changed how they presented pain. Because they were used to managing pain, they did not always display distress in ways clinicians recognised as urgent. Yet even when they did show distress, this could be reframed as anxiety:

I manage myself. I can make a sentence. My heart rate and my blood pressure are fine. ... I'm just so used to managing it that I'm not going to sit there like, 'Ahhhh'. There have been times where I have been like that, and I still didn't get taken seriously. Even when my pain was severe, and I was showing the signs, they just... Said I had 'white coat syndrome' ... so they tried to blame it on anxiety.

This perspective shows that participants were not only required to report pain, but to display it in a clinically acceptable way. The participant's composure could make pain seem less serious, but visible distress could be psychologised. This created a no-win situation: both managing pain and showing pain could work against participants. Pain legitimacy therefore depended not only on what participants felt, but on whether their pain performance matched what others expected.

Hallström's (2024) concept of a "pedagogy of pain" is useful here because participants were not simply reporting pain; they were learning how pain needed to be presented in order to become credible. However, the present findings suggest that these standards were unstable. Participants could be dismissed for appearing too well, too distressed, too knowledgeable, or too medication-seeking. Credibility was therefore not

attached to pain severity alone, but to how bodies, emotions, scans, and requests for relief were interpreted by others.

This finding further complicates the literature on gendered pain credibility. Existing research suggests that women's pain may be psychologised or interpreted through assumptions about emotionality and coping (Samulowitz et al., 2018). Participants' accounts in this study show how difficult these credibility standards were to satisfy. Pain could be dismissed when participants appeared composed, but also psychologised when they appeared distressed. It could be questioned when scans were normal, but also minimised when symptoms persisted after diagnosis or treatment. This suggests that participants were navigating unstable standards of credible pain, where both too much and too little visible distress could undermine recognition.

Psychologisation was particularly damaging because it encouraged participants to doubt their own interpretation of pain. One participant reflected on how age, gender, and limited family medical knowledge shaped her trust in professional dismissal:

But I think when you're young and also female and ... my family's not particularly educated, with no doctors in the family or anything. You just take what the professionals say as that must be right, and I must be imagining it or something.

This quote is significant because it highlights how dismissal could become internalised. The participant did not simply reject professional explanations; she questioned whether they might be right. Psychologisation therefore had consequences

beyond the consultation. It shaped self-trust, making participants wonder whether they were exaggerating, imagining, or misreading their own pain.

Stigma shaped whether pain was taken seriously. Some participants described pain being attributed to body size, emotional weakness, attention-seeking, or inability to cope. In these accounts, stigma shifted responsibility for pain onto the participant rather than prompting further investigation:

Then I went to see [a gynaecologist] an hour away from where I live, and he purely told me in front of me and my mother, 'Oh, you're just fat. If you lost some weight, you wouldn't have that issue.' ... I cried. I broke down crying.

Here, weight stigma displaced clinical curiosity. The participant's pain was not approached as something requiring investigation, but as something caused by her body size. This mattered because stigma narrowed the range of possible meanings attached to pain. Rather than being treated as a symptom requiring care, pain became something the participant was positioned as responsible for.

Seeking pain relief could threaten legitimacy. Participants described being offered inadequate relief in emergency or clinical settings, while also fearing that requesting stronger medication would make them appear drug-seeking:

And if I'm going to A&E because I am that bad, pretty much the best option I have is an anti-inflammatory shot to the bum/thigh to just calm that nervous system down. But that's it, because if I was to ask for anything else, that opens up a completely

different can of worms in terms of, 'Well, you've just walked in asking for morphine.'

Yes, because I'm in enough pain that morphine will bring me back down.

This quote captures the moral tension surrounding pain relief. The participant knew what level of relief might help, but also knew that asking for stronger medication could change how she was perceived. Rather than being treated simply as evidence of severe pain, the need for stronger relief could become a source of suspicion. Pain medication therefore became another site where participants had to manage credibility and legitimacy.

Participants' accounts also show that the pressure to display pain in a credible way could become especially intense when seeking pain relief. Rather than being treated only as people in pain, some participants felt they had to defend the legitimacy of their need for medication or acute care. This reflects broader concerns in gendered pain literature about how women's reports of pain may be doubted, minimised, or interpreted through suspicion (Samulowitz et al., 2018). In the present study, this suspicion did not simply delay relief; it also shaped how participants understood themselves as patients. Seeking help could become emotionally risky because it required participants to balance expressing the severity of pain with avoiding being seen as exaggerating, anxious, or medication-seeking.

For some participants, inadequate pain management led to desperation and shame around medication use. The need to keep searching for stronger relief could make

participants feel morally judged, even when medication was being used simply to get through severe pain:

I mean, to be honest, I felt like I was a druggie because I was taking that many painkillers, and when those painkillers stopped working, what's the next one that I can get my hands on? It was always looking for something stronger. And that side of things, it is real. Because Panadol just doesn't cut it. ... And it's like, well, I'm in intense pain. So I was constantly dosing up on pain medication just to try and get through.

This account sheds light on how the search for relief could become entangled with stigma. The participant's use of the word "druggie" reflects not only medication use, but the shame attached to needing stronger pain relief. When severe pain is inadequately treated, participants may be pushed toward forms of self-management that are then morally judged. This reinforces the double bind of pain legitimacy: needing relief confirms the severity of the pain to the participant but may undermine credibility in others' eyes.

This finding extends gendered pain literature by showing that suspicion was not limited to whether pain was believed, but also shaped whether participants felt morally entitled to seek relief. Samulowitz et al. (2018) show that women's pain may be undertreated or psychologised, while Ellis, Tewhaiti-Smith, et al. (2024) document concerns about being perceived as drug-seeking in Aotearoa New Zealand endometriosis care. In the present study, this suspicion became internalised as shame. Participants' need for stronger medication confirmed the severity of pain to themselves, yet risked

undermining their credibility to others. Pain relief therefore became another site where legitimacy had to be managed.

Overall, participants' accounts show that pain had to "look right" to be believed, yet the standards for believable pain were unstable and difficult to satisfy. Normal scans, controlled presentation, visible distress, body size, and medication requests could all become reasons for dismissal. These findings support feminist health scholarship showing that women's pain may be underestimated, psychologised, or interpreted through assumptions about emotionality, coping, or exaggeration. However, the present findings add nuance by showing that participants were not simply disbelieved; they had to continually manage how their pain appeared, how much distress they showed, how strongly they advocated, and how their requests for relief might be interpreted. Pain legitimacy was therefore shaped by how others read participants' bodies, emotions, and requests, rather than by pain severity alone.

The Burden of Proof

Because pain was normalised and dismissed, participants often became responsible for proving it. Pain was not automatically treated as legitimate; it had to be made medically legible. Participants described researching symptoms, learning medical language, seeking second opinions, bringing information to appointments, and persisting through referrals. This advocacy could be empowering, but it was also exhausting and unevenly available.

One participant described having to gather information for herself rather than receiving it from professionals. This made information-seeking part of the labour of legitimising pain, because she had to learn what to ask before useful knowledge became available:

Like all this information I've gathered over the past three or four years is because I've had to ask very specific questions or I've spoken to people online who have said, 'You should try this'. It's all about me trying to get the information rather than professionals, leading surgeons, giving me the information.

Implicit in this response is how information-seeking became patient labour. The participant's knowledge was not only a sign of empowerment; it was evidence of a gap in care. She had to ask specific questions and search elsewhere because information was not readily offered. The burden of proof therefore involved more than reporting pain. Participants had to become informed enough to make pain understandable and actionable within clinical systems.

The ability to advocate was unevenly distributed. Participants with family knowledge, health literacy, professional healthcare backgrounds, or confidence navigating medical systems recognised these as forms of privilege:

And knowing my mum's journey with it [endometriosis], so I think I feel quite grateful that I had the support of her and knowing what it was. And I also have to acknowledge that I am quite health-literate from being a [healthcare] student at that time and now a [healthcare professional]. ... And as someone that works in health

and was still struggling, I was like, ‘Oh my God, this must be so hard for people. Like this is wild.’

This extract makes visible the unequal conditions under which pain advocacy takes place. Even with family knowledge and health literacy, the participant “was still struggling”. Her reflection suggests that self-advocacy should not be understood simply as an individual skill. It depends on access to language, confidence, education, support, and familiarity with health systems.

The burden of proof described by participants aligns with Carel and Kidd’s (2014) concept of epistemic injustice in healthcare, where patients’ knowledge of their own bodies may be given less credibility than professional or institutional forms of knowledge. It also connects with New Zealand research showing that dismissal and self-advocacy recur across endometriosis patient accounts (Ellis et al., 2023; Ellis & Wood, 2025). However, the present findings complicate any simple framing of self-advocacy as empowerment. Participants’ research, persistence, and use of medical language could increase agency, but these strategies were also required because care was not freely offered and pain was not automatically believed. Advocacy was therefore not only an individual strength; it was labour produced by unequal credibility.

Advocacy was double-edged. Participants were expected to speak up for themselves, but doing so could be interpreted as overstepping:

Well, that appointment, it was a back-and-forth discussion, and it got really intense, especially with me standing up for myself. I noticed that when I speak up for myself,

and I've done readings and research on the treatment that they proposed to me, they treat me like I'm overstepping. I get treated like I'm talking out of what I'm supposed to.

This shows how participants could be caught between two contradictory expectations: they were expected to advocate for themselves, but could be judged when they did so too forcefully or knowledgeably. Hallström's (2024) discussion of becoming a patient is useful here. Participants were not only seeking treatment; they were trying to become recognisable as legitimate patients within systems that did not always treat their embodied knowledge as credible.

Participants described a paradox of self-management. When they managed symptoms effectively, their distress could become less visible. This created a cruel choice: manage symptoms and risk not being taken seriously, or deteriorate enough for the system to recognise severity.

The other annoying thing is that my iron levels are adequate. I'm not anaemic, and I'm not showing other issues with the blood loss. And all my other blood tests and everything, they're all fine. ... So I'm not deteriorating in that regard. So, that's because I'm actively trying to make sure that I'm maintaining my health. So, it kind of goes against me. I could stop doing that, and deteriorate and see what happens. But I don't want to because I still want to live my life.

This account complicates the meaning of functioning. Stable results did not mean that symptoms were minor; they reflected active work to prevent deterioration. Yet this

work made suffering less visible. Participants could therefore be penalised for coping. Their efforts to manage symptoms could weaken the evidence used to justify care.

Years of dismissal bred distrust. Some participants described withholding information, discontinuing medication, or lying about whether they had followed treatment recommendations because they did not feel heard or involved in decision-making:

That was after me lying about - they gave me medication, and ... I said, 'Oh yeah, it's not working'. Even though I never took it because I knew if I took it and even if it didn't work, they would still kind of push me onto another medication. So I just lied, which helped in my favour.

This quote demonstrates how distrust could alter clinical behaviour. The participant's decision to lie was not simply non-compliance; it was a strategy within a system she felt did not listen to her preferences. When participants' embodied knowledge was disregarded, they could begin managing clinicians' responses rather than openly collaborating in care.

The burden of proof therefore involved more than persistence. Participants had to balance trust and scepticism, compliance and resistance, self-knowledge and medical authority. Advocacy could lead to recognition, but it was also emotionally costly and unequally available.

This finding further develops the idea of epistemic injustice in healthcare by showing how unequal credibility shaped participants' practical behaviour. Participants did not only feel dismissed; they adjusted how they spoke, what they researched, how they

presented themselves, and sometimes what they disclosed in order to navigate systems where their embodied knowledge was not always trusted. This suggests that the burden of proof was both emotional and strategic. Participants had to manage the relationship between self-knowledge and medical authority while continuing to live with pain.

Diagnosis as Validation and Fragile Legitimacy

Diagnosis held significant emotional meaning because it provided evidence that pain had a material basis. After years of normalisation, dismissal, or uncertainty, diagnosis could offer validation that participants were not imagining, exaggerating, or failing to cope with ordinary pain. For several participants, the immediate question after surgery was whether anything had been found:

So had my first lap [diagnostic laparoscopy], and I remember my specialist saying to me, 'What is your biggest fear?' And I said, 'That you're going to go in and not find anything.' Like we'd already got past the point of someone just doesn't think it's purely in my head or that I'm being melodramatic. Now it was, if you go in and come back out and tell me nothing's wrong, then what is wrong? That was my biggest concern. ... I remember waking up and asking my mum, 'Did they find anything?'

This extract shows that diagnosis mattered because it could settle a deeper question about reality and credibility. The participant was afraid that if nothing were found, she would be returned to uncertainty about whether the pain was real. The question "did they find anything?" therefore carried the weight of previous disbelief.

Furthermore, for many participants, diagnosis brought relief because it provided a name and explanation for pain that had disrupted their lives:

It was like the happiest I ever felt because of that validation. And I remember saying to my mum, 'I should be like crying or really sad because, oh no, I have this really bad disease.' But she was also happy. And she was like, 'No, you're so right to be happy because for years you've been in pain and your life has been ruined. And now you finally have a reason for that.'

This interaction reveals diagnosis as psychosocial recognition. The participant was not happy to have endometriosis; she was relieved that her pain finally had an explanation. Diagnosis reorganised the meaning of past pain, transforming it from something confusing or doubted into something legitimate.

This finding aligns with research that frames endometriosis diagnosis as a struggle for recognition (Hallström, 2024). Diagnosis mattered because it could confirm that pain had a recognised basis and counter earlier messages that symptoms were normal, exaggerated, or imagined. In the present study, however, diagnosis was not only a medical event; it was also an emotional and interpretive turning point. It reorganised the meaning of past suffering by allowing participants to re-read earlier pain as legitimate rather than as weakness, overreaction, or low pain tolerance. At the same time, validation was emotionally complex. Diagnosis could bring relief, but it could also produce grief, anger, shock, or fear when participants realised how long pain had been dismissed or how extensive the disease had become.

However, diagnosis did not permanently secure legitimacy. Some participants continued to experience dismissal when pain persisted after treatment or did not follow expected clinical narratives:

But I was literally told that I was going to be refused treatment until I'd gone under some sort of psychiatric or psychological evaluation because they had essentially convinced themselves from the five minutes I'd sat in front of them that because I'd got a diagnosis, I'd now worked all of this up in my head that it was worse.

This quote exposes how diagnosis could paradoxically become part of a new form of dismissal. Rather than securing legitimacy, the diagnosis was interpreted as something that intensified the participant's focus on pain. Recognition was therefore unstable. Even after medical confirmation, pain could be psychologised if it continued beyond expected treatment timelines.

One participant described how the effects of prior disbelief could persist after diagnosis. Even when medical evidence was available, earlier experiences of being doubted made it difficult to trust that others would now recognise the pain as legitimate:

I think that's when I started internalising a lot of it, and I didn't share it, not even with my parents. Because I was like, what if they don't believe me either? Yes, medically you can see whatever, but still, what if they don't believe me? What if I tell someone and they're like, 'Oh, get over it, you know, like suck it up, take an extra Panadol or something'?

This extract demonstrates that medical evidence did not necessarily resolve social disbelief. The participant still feared that others would minimise her pain, even after diagnosis made the condition visible in medical terms. Diagnosis could validate pain, but it did not automatically undo the psychological effects of earlier invalidation. Legitimacy, once damaged, remained fragile because the participant continued to anticipate disbelief, dismissal, or pressure to simply tolerate pain.

The present findings therefore support literature framing diagnosis as recognition, but also extend it by showing that recognition may remain conditional after diagnosis. Diagnosis could validate pain, but it did not automatically repair the effects of earlier disbelief or guarantee that ongoing pain would be taken seriously. When pain persisted, recurred, or exceeded expected treatment narratives, participants could be returned to familiar patterns of psychologisation and doubt. Legitimacy was therefore fragile because it depended not only on diagnosis, but on whether pain continued to fit socially and clinically acceptable explanations.

Overall, this theme shows that participants' pain had to become legitimate across multiple contexts: within themselves, among family and peers, and within healthcare encounters. The findings align with existing research showing that endometriosis-related pain is frequently normalised, dismissed, and shaped by gendered assumptions about menstrual and reproductive pain. However, they also extend this literature by showing that legitimacy was repeatedly negotiated rather than achieved once and for all. Pain was made ordinary through educational, familial, and social silence; questioned when it did not appear clearly on scans or in expected forms of distress; made into evidence through

participants' own advocacy; and sometimes re-psychologised even after diagnosis. Pain legitimacy was therefore not a single moment of being believed, but an ongoing psychosocial process shaped by knowledge, credibility, clinical evidence, diagnosis, treatment response, and social recognition. Having examined how participants struggled to have pain recognised as real and worthy of care, the next theme considers how care pathways shaped how long participants remained in pain, how much uncertainty they carried, and how much agency they felt while seeking help.

Theme 2: Waiting in Pain: Care Pathways, Uncertainty, and the Cost of Access

In this theme, the healthcare system and care pathways are understood as part of the psychosocial context of persistent pain. It is not intended as a general critique of the healthcare system. Rather, it analyses how access, delays, costs, and fragmented care affected the lived experience of pain. Participants' accounts suggest that private healthcare, insurance, health literacy, and socioeconomic privilege did not necessarily remove pain or guarantee better long-term outcomes. However, these resources shaped participants' uncertainty, access to relief, sense of agency, and experience of feeling abandoned or supported while living with pain.

Waiting for care was not simply time before treatment; it was time spent continuing to live with pain. Paying for private healthcare was not simply a financial decision; it shaped whether participants could reduce uncertainty or access care sooner. Fragmented communication was not only inconvenient; it required participants to retell painful histories and repeatedly carry the burden of coordination. Together, these experiences

show that care pathways shaped not only access to treatment, but also the duration, uncertainty, and emotional burden of living with pain. This theme shows that agency in care was not simply an individual trait, but was enabled or constrained by material resources, health literacy, referral pathways, and the responsiveness of healthcare systems.

Diagnostic timing varied across participants' accounts, but several described living with symptoms for many years before receiving a diagnosis, with some gaps between symptom onset and diagnosis lasting more than a decade. These histories are important for interpreting how participants made sense of pain legitimacy, healthcare navigation, uncertainty, and persistent pain. However, diagnostic timing should not be treated as a simple indicator of pain severity or outcome. Some participants who were diagnosed earlier continued to describe ongoing pain and psychosocial impacts, while others described long delays before pain was medically recognised. This means that delay mattered not only as a measure of time to diagnosis, but as part of the wider care pathway through which pain was interpreted, managed, and made more or less liveable.

This theme is organised into four subthemes: Access shaped agency; Paying for time, not cure; Waiting as suspended life; and Fragmented care and emotional labour.

Access Shaped Agency

Participants' accounts suggested that access to care was unevenly distributed. Money, insurance, family support, location, health literacy, and the ability to navigate public and private systems shaped what options were available. Importantly, these

resources did not necessarily mean participants became pain-free. Rather, they shaped how much control participants had while living with pain.

One participant reflected on the privilege of having options. Her account shows that access was not only about receiving treatment, but about having enough support, flexibility, and resources to make choices around quality of life:

So, I think I'm also very lucky with sort of being able to go back [home]. I'm not stuck, and I can do things that are right for my quality of life. I can take time out from work. So, I'm very lucky. And also with the GP and especially in having that access. Also, I could go privately for the surgery, so that wasn't like some people. If I didn't have that, I'd be waiting and waiting and waiting. ... So that's sort of not fair.

This narrative shows how access shaped agency. The participant's ability to rely on parental support, take time out from work, access a GP, and use private surgery enabled her to make decisions based on quality of life rather than simply endure the pace of the public system. Her reflection that this was "not fair" shows that while pain itself was not distributed by privilege, options for responding to pain were. Agency was therefore materially enabled, shaped by social and economic conditions as well as individual resilience or persistence.

These accounts align with existing Aotearoa New Zealand research showing that access to endometriosis care is shaped by diagnostic delay, referral pathways, healthcare knowledge, and uneven availability of timely support. Tewhaiti-Smith et al. (2022) found that people with endometriosis and chronic pelvic pain symptoms often saw multiple

doctors before receiving a diagnosis, while Ellis, Meador, et al. (2024) highlight the importance of general practitioners' knowledge, confidence, and referral practices in shaping care. The present findings build on this literature by showing how access was experienced as agency. Participants with money, insurance, family support, flexible work, or health literacy did not necessarily have less pain, but they often had more options for responding to pain. Access therefore shaped not only treatment pathways, but also how much control participants felt they had while living with uncertainty.

Participants explicitly recognised that pain was experienced within unequal social and economic conditions. This mattered because access to care was not only shaped by pain severity, but by ethnicity, socioeconomic position, money, private options, and the ability to keep seeking help:

And then think about when you talk about the socioeconomic aspects of New Zealand. I'm a privileged white female, and even I'm having a hard time. Imagine I'm not a privileged white female. I'm brown, and I come from poverty, and I can't afford to go to the doctors. I can go private, so I often think about that. I'm really lucky, and it could be totally different. And it is totally different for so many other people in New Zealand.

This account places persistent pain within social inequality. The participant does not suggest that privilege made her pain easy; rather, she recognises that even with privilege, the journey was difficult. This makes the inequality more striking. If someone with resources still struggled to access timely and adequate care, those with fewer resources

may carry even greater uncertainty, delay, and distress. Her reflection therefore shifts the analysis away from pain as only an individual medical experience and toward the wider social conditions that shape who can access care, how quickly, and at what cost.

This finding also connects with equity concerns in the Aotearoa New Zealand literature. Dunning et al. (2025) identify ethnicity-based variation in referral and surgical waitlisting pathways for endometriosis and persistent pelvic pain, while Ellis, Tewhaiti-Smith, et al. (2024) highlight longer diagnostic delays, barriers to culturally safe care, and poor healthcare experiences among Māori and Pasifika patients. Although the present study does not provide a comprehensive analysis of ethnic inequity, participants' accounts support the broader point that access to care is not evenly distributed. The ability to shorten waiting, choose clinicians, pursue private options, or persist through fragmented pathways was shaped by social and material resources as well as individual determination. This suggests that agency in care should not be understood simply as personal assertiveness; it is also produced through structural conditions.

Access was about being able to choose clinicians who were more likely to understand and respond appropriately. For participants with financial or family support, choosing a clinician could create a pathway that felt more responsive to their needs:

I'm privileged enough that I was able to select a gynae and see them privately and then do the procedure [as an] outpatient publicly. So, I was privileged enough to be able to do that and have my parents support me on that. But even just if you can

select the people that are right for you and that will take in your needs and what you want. Because otherwise you just don't get anywhere.

This account shows that agency in care was unevenly distributed. Being able to select a clinician meant being able to pursue a pathway that felt more aligned with the participant's needs. Without that option, participants could feel stuck in systems where pain was not understood, prioritised, or acted upon. Access therefore shaped not only treatment opportunities, but the emotional experience of being able to do something about pain.

Paying for Time, Not Cure

For many participants, private care represented a way to shorten uncertainty or access attempts at relief more quickly. However, participants did not necessarily describe private care as a cure. Rather, private care could buy time, speed up appointments, or provide access to specialists, while pain itself often remained complex and unresolved. This distinction helps show that better access did not necessarily produce better outcomes; rather, it shaped the psychosocial conditions in which participants lived with pain.

One participant expressed frustration that “paying out of pocket” was the only way she felt she had received adequate care. Her account suggests that private care was not experienced as luxury, but as a route to care she believed should have been available through ordinary pathways:

Going out of my way and paying out of pocket is the only way that I've received standard care. Which I feel should be standard care. It's not, but that speaks volumes of our public system. More so, I think, than anything else, that they're just not equipped or they're just not willing. I don't know what. ... It's a bigger picture than what people think it is. Because it's not as simple as just going to the doctor, getting a referral and finding out, it's so much trial and error.

This quote captures the frustration of paying for care that the participant believed should have been ordinary. The phrase "standard care" is important because private care is not framed as a luxury or convenience, but as the level of care she felt should already have been available. Paying privately therefore intensified the psychosocial burden of pain, because recognition, responsiveness, and the chance to move forward felt dependent on personal resources.

Another participant's account shows both the value and the limits of private care. On one hand, private care could interrupt prolonged confusion and help participants access answers or treatment sooner:

I think if I hadn't been able to go to a private doctor, I think I would still be now confused and in so much pain ... it would be so much worse now. So, I think the public health system was so bad and even the years of them just telling me there's nothing we can do about it and get used to it and stuff. And take different painkillers. That was so, so terrible.

This account shows how private care could reduce uncertainty. The participant imagines that without private care she would still be confused and in pain. The difference was not necessarily that private care removed pain, but that it changed the duration of not knowing and not being helped. In this way, access shaped the emotional burden of pain by shortening the period in which participants felt abandoned or without direction.

However, the same participant complicated the idea that private care resolved the problem. Faster access could provide movement, prescriptions, or surgery, but it did not necessarily provide certainty or cure:

But the private health system is also not great, because there's still no answers. All they can do is just speed things up. They give you a prescription for something that you need now instead of in five years, or they give you surgery now instead of in five years. But it doesn't fix it. I guess in the long run, I'm just paying more money for the same. No answers or no fix.

This reflection is pivotal because it shows that private care could speed up access, but it did not necessarily provide a cure, certainty, or freedom from pain. The participant was “paying more money for the same no answers or no fix.” This suggests that the key psychosocial difference was not always outcome, but time, uncertainty, and agency. Access changed how participants moved through pain, even when it did not end pain.

These findings extend existing literature on healthcare access by showing that private care was often valued for time, responsiveness, and perceived momentum rather than as a guarantee of cure. Existing research has documented long diagnostic delays and

repeated healthcare encounters in Aotearoa New Zealand endometriosis care (Ellis & Wood, 2024; Tewhaiti-Smith et al., 2022). The present findings show how these delays shaped participants' decisions to seek private care when possible. Paying privately could reduce waiting, create a sense that someone was listening, or make next steps feel more available. However, participants' accounts also complicate any simple assumption that private care solved the problem. Private care could buy speed, attention, and choice, but it did not necessarily remove persistent pain or resolve the need for ongoing support. This is consistent with clinical literature emphasising that endometriosis has no medical or surgical cure and that pain may persist or recur despite treatment (As-Sanie et al., 2025).

For participants who could not afford private care, being directed toward private options could feel like being forsaken. One participant explained, "I can't get an appointment. The GPs just told me, now try and go private. But I can't afford private, so you just have to suffer. You just have to absolutely suffer."

This demonstrates the emotional force of financial exclusion. Private care was presented as a pathway, but for someone unable to pay, it was not a real option. The result was not simply delay, but abandonment. Pain became something the participant had to continue enduring because the available pathway was financially inaccessible.

This finding is important in light of research on the economic burden of endometriosis and chronic pelvic pain in Aotearoa New Zealand. Tewhaiti-Smith et al. (2025) identify substantial costs associated with endometriosis and chronic pelvic pain, including healthcare, productivity, and carer costs, and argue that diagnostic delays, poor

healthcare access, and suboptimal symptom management are likely modifiable contributors to this burden. Participants' accounts give qualitative meaning to these economic findings. Cost was not only an abstract financial measure; it shaped whether participants could act, how long they remained in pain, whether families absorbed the burden, and whether care felt possible or out of reach. In this sense, paying for care was also paying for reduced uncertainty, faster recognition, and the possibility of agency.

Overall, paying privately shaped the psychosocial experience of pain by changing how much uncertainty participants had to carry and how quickly they could access attempts at relief. However, the data do not suggest that privilege made pain disappear. Instead, privilege shaped whether participants could buy time, choice, and partial agency while living with pain.

Waiting as Suspended Life

Waiting was a central feature of participants' experiences of care. Participants described long waitlists, delayed follow-up, postponed surgery, and periods where no further support was available. Waiting was not experienced as passive time. It was time spent continuing to live with pain, uncertainty, functional limitation, and fear that symptoms might worsen.

One participant described being told to wait months despite feeling she had already done everything possible to manage her pain. This waiting was not passive, because she remained responsible for living with pain while having no clear next step available:

You don't really know what to do or how because you can't really help yourself do anything with it any further. Because for me, I've done everything possible, so there's nothing else to do. So from now [February] until December, I don't know what to do. Nothing to help the pain, can't go back to my specialist 'cause he said, 'Come meet me in December.'

This extract shows waiting as suspended agency. The participant was not simply waiting for an appointment; she was waiting while still in pain and with no meaningful next step. Having already exhausted what she could do independently, she was left both responsible for managing pain and unable to change the situation meaningfully. Waiting therefore became part of the pain experience itself, intensifying helplessness and uncertainty while care remained out of reach.

Delays could continue even when pain severely affected mobility, medication effectiveness, isolation, and mental health. In these moments, the pace of care could feel dangerously misaligned with the urgency of participants' lives:

I had an appointment with my GP, and I said, I really need this surgery. I'm suffering really, really badly. I can't move. I can't walk. I'm homebound. I'm being isolated. The medication, like Celebrex, I've been given codeine. Morphine. None of it is working. ... So a lot of the things that I've waited for is basically due to the admin of how fast you're seeing through each appointment through each process. By the time they saw me, I suppose I was hanging by a thread on life.

This account captures how the pace of care did not match the participant's lived urgency. Her pain was not only physical; it had made her homebound, isolated, and unsupported by medication. Yet she remained dependent on appointments, referrals, and treatment processes that moved more slowly than her suffering. The phrase "hanging by a thread on life" captures the psychological weight of waiting while pain continued to escalate.

These accounts align with literature showing that diagnostic delay is a major feature of endometriosis experience, but they also extend this literature by showing what waiting felt like while participants remained in pain. Internationally, diagnostic delay is often reported as a gap between symptom onset and diagnosis, and Aotearoa New Zealand research similarly documents long delays and repeated healthcare encounters (As-Sanie et al., 2025; Ellis & Wood, 2024; Tewhaiti-Smith et al., 2022). The present findings show that waiting was not empty or passive time. It was time spent managing symptoms, uncertainty, work disruption, financial pressure, treatment decisions, and fear about the future. Waiting therefore became part of the psychosocial burden of persistent pain rather than merely a delay before care.

Delays affected life planning. Participants could struggle to work, study, or make commitments while waiting for treatment or surgery:

They weren't willing to give me the time off, but I knew my condition was getting worse, so it was best for me to step away until I was ready to go back. ... And it took two years after I'd left my job before I got my surgery. And my partner's always on

me about, 'When would you like to go back to work?' ... It's like I can't put myself in that situation again.

This reflection demonstrates that the effects of delayed surgery persisted beyond the waiting period. The participant's hesitation about returning to work was therefore not only about current pain, but about the possibility of being caught in the same cycle again: reorganising her life around surgery, losing employment stability, and then having care delayed. Waiting had created a lingering uncertainty that shaped how she imagined work, recovery, and the future.

Delays created fear about what might happen while participants waited. This fear was not only about current pain, but about what might be happening inside the body and what future possibilities could be affected:

They need to do something about the delays because like I said, my daughter and so many other women her age, who are only 19, they're at the start of it. They could be having damage to their fertility that these delays are affecting, you know, and that's really scary. And also their quality of life, their ability to study, to get on with their life.

This quote shows how waiting could produce fear about both present and future loss. The participant links delay not only to fertility concerns, but also to quality of life, study, and the ability to "get on with life." Waiting was therefore emotionally charged because participants did not know what was happening inside their bodies or what opportunities might be lost while care was delayed.

This finding also supports the COMPASS model's emphasis on agency, sense-making, systemic factors, and access to care in endometriosis-related persistent pain (Pickup et al., 2025). Participants' accounts showed that care pathways shaped whether they could make decisions, plan ahead, trust their bodies, or feel that relief was possible. Waiting suspended more than treatment; it suspended life plans, work and study participation, fertility decisions, and emotional certainty. This extends existing research by showing that healthcare delay is not only a system-level problem, but a lived psychosocial condition that can reshape time, identity, and agency.

Overall, waiting prolonged suffering by extending the period in which participants lived without answers, relief, or clear direction. Where private care was not financially possible, waiting became the only available pathway. This reinforced the unequal nature of care: some participants could reduce waiting by paying privately, while others remained suspended in pain.

Fragmented Care and Emotional Labour

Participants described care as fragmented and administratively exhausting. They had to manage referrals, chase appointments, repeat histories, and coordinate information across services while already living with pain. One participant described being missed for her follow-up appointment after surgery and struggling to contact her surgeon:

There seemed to be some kind of miscommunication, or something happened, and I got missed. So, I didn't have a follow-up appointment for like 6 months after my surgery. And I was struggling to find how to contact them because the messages I

had received were from their scheduling person, but not actually from the team.

And I found it really hard to speak to the person I needed to speak to.

This quote shows how fragmented communication could leave participants without reassurance, guidance, or clear pathways back into care. The participant was not only recovering from surgery; she was also trying to work out who was responsible for follow-up and how to reach the right person. Fragmentation therefore intensified the psychosocial burden of pain by making participants responsible for continuity at a time when they needed care to be coordinated for them.

For people with complex pain histories, repeatedly retelling their story was emotionally exhausting. This repetition was not simply administrative; it required participants to revisit pain, dismissal, surgery, uncertainty, and ongoing suffering each time they encountered a new provider:

Why aren't we on one big system where all our notes are accessed through a nationwide portal? Why is it that we have to repeat our stories to every doctor, every practise nurse, every GP? We have to tell our whole history again. And we're exhausted.

This extract captures the burden of repetition. Retelling a pain history was not a neutral administrative task when that history included dismissal, surgery, fear, and ongoing suffering. Fragmented systems required participants to carry continuity that the system did not provide. This added to the emotional labour of living with persistent pain, as participants had to keep making their history legible across disconnected points of care.

These accounts align with literature emphasising patient-centred care, shared decision-making, coordinated care, and the need for clear, validating information in endometriosis management (Fang et al., 2024; Ministry of Health, 2020; Pickup et al., 2025). Fang et al. (2024) highlight the importance of long-term, comprehensive, coordinated, and patient-centred care, while New Zealand guidance aims to support early recognition, primary care management, multidisciplinary support, and equity of access and outcomes (Ministry of Health, 2020). However, participants' accounts suggest a gap between these aims and lived experience. Fragmented care meant that participants often became responsible for continuity: repeating histories, chasing referrals, processing complex medical information, and identifying the next step while already living with pain. This finding extends literature on diagnostic delay and access by showing that the burden of care pathways was not only waiting for services, but also carrying the administrative and emotional labour of moving between them.

Time-pressured care shaped how participants processed pain-related information. Participants recognised that clinicians were stretched for time, but short appointments could leave them without adequate information and explanations:

What I find is the trickiest thing is I know that people are really stretched for time. So to me, what I've observed is, it seems like they get used to saying a short spiel that kind of covers some of the information. And for some people that's enough, and that's all they need to hear, and that validates them. But for other people who have more questions or need information shared in a different way, it doesn't work.

This account avoids a simple critique of individual clinicians. The participant recognises time pressure as a systemic constraint and explains how standardised communication can fail to meet diverse patient needs. For participants living with persistent pain, information was not merely factual; it shaped uncertainty, agency, and emotional safety.

Another participant described receiving heavy medical information in a way that left little room for human impact. Although information was necessary, the way it was delivered could leave participants to process the emotional meaning of that information alone:

I would not feel present, especially when I was going through the medical discussions with my doctors and with the surgeons. The information was so heavy, and the way that they said it to me. It was just so matter-of-fact; it made me feel like, oh, wow, they're delivering it ... in a way where there's no human impact. And so I would come home. I would think about what I was told, review what I was told and give myself time to process what they told me.

This reflection shows how clinical communication could displace emotional processing into private time. The participant was given information that affected her body, pain, and future, but the delivery felt detached from its human meaning. Her description of not feeling “present” suggests that the weight of the information exceeded what she could process in the moment. Matter-of-fact care therefore left her to carry the emotional labour of making sense of pain-related decisions after the appointment had ended.

This finding adds nuance to discussions of healthcare access by showing that receiving information is not the same as feeling supported to understand or carry it. Participants did not only need clinical facts; they needed communication that recognised the emotional weight of pain, surgery, fertility, treatment decisions, and uncertainty. This aligns with literature emphasising patient-centred care, shared decision-making, and the need for clear, validating information in endometriosis management. In the present study, matter-of-fact communication could leave participants to process the human meaning of medical information alone. Emotional labour was therefore produced not only by waiting and fragmentation, but also by the way information was delivered.

Overall, this theme shows that healthcare pathways shaped the psychosocial experience of pain through access, cost, waiting, fragmentation, and communication. The findings align with existing Aotearoa New Zealand literature documenting diagnostic delay, repeated healthcare encounters, access barriers, economic burden, and the importance of primary care and referral pathways. However, they extend this literature by showing how these system-level issues were lived emotionally, practically, and relationally by participants. Waiting was not simply time before care; it was time spent in pain, uncertainty, self-advocacy, financial strain, and suspended life planning. Private care and insurance could increase agency, but they did not necessarily remove pain or guarantee lasting relief. Fragmented care further intensified the burden by making participants responsible for continuity, information-seeking, and emotional processing while already managing symptoms. This suggests that healthcare systems are not merely the backdrop against which endometriosis-related persistent pain is experienced; they actively shape

how long pain is endured, how much agency people feel, how much uncertainty they carry, and whether care feels accessible, coordinated, and humane. While this theme has focused on care pathways, the next theme turns to participants' everyday lives, examining how persistent pain shaped work, study, relationships, disclosure, intimacy, and social participation.

Theme 3: Living With an Unpredictable and Invisible Body

This theme examines the social and external impacts of living with endometriosis-related persistent pain. Participants had to organise work, study, relationships, intimacy, social plans, and public behaviour around pain that was unpredictable, invisible, and difficult for others to understand. It considers how pain affected participation, disclosure, masking, social expectations, and the practical management of everyday roles. Although these experiences had psychological consequences, the emphasis here is on how pain was negotiated in the social world: how participants appeared to others, how they explained or concealed symptoms, and how they adapted life around an unpredictable body.

A central feature of this theme is the gap between internal experience and external appearance. Participants could be in severe pain while appearing well, functional, or composed. Because pain was not always visible, they had to manage disclosure, masking, over-explaining, and other people's interpretations. Pain therefore created social labour. Participants had to make pain understandable while also managing the risk of judgement, disbelief, or being seen as unreliable.

This theme is organised into four subthemes: Pain that cannot be scheduled; “You look fine”: social invisibility and disclosure; Performing normality; and Organising life around pain.

Pain That Cannot be Scheduled

Participants described pain as unpredictable, sudden, and difficult to plan around. Pain could appear without warning, intensify quickly, or interrupt an otherwise ordinary day. Everyday life therefore became provisional. Participants could make plans, but they could not rely on their bodies to allow those plans to happen. One participant captured the speed with which pain could change a day:

For some people it’s day by day, for others it’s hour by hour. Things change like that. You could be waking up, feeling so mint, have a shower, get in your car, get to work, and your world could fall apart around you within the first half an hour of your day starting.

This explanation demonstrates that participants were not only managing pain when it arrived; they were managing the possibility that pain could arrive at any time. This matters because unpredictability changed the meaning of planning. Participants could not simply organise life around known pain days or predictable cycles; they had to live with the possibility that capacity could disappear suddenly. This made everyday commitments feel provisional, even when participants wanted to remain reliable.

This finding aligns with de C Williams and McGrigor’s (2024) description of endometriosis pain as persistent, cyclical, and unpredictable. Participants’ accounts in

the present study support this, but also extend it by showing how unpredictability shaped the social organisation of everyday life. Pain was not only difficult because it hurt; it was difficult because participants could not know when their capacity would disappear. This meant that ordinary commitments, such as going to work, attending university, seeing friends, or completing daily tasks, became conditional on a body that could not be fully planned around. Unpredictability therefore made life provisional, requiring participants to organise not only around pain itself, but around the possibility of pain.

The unpredictability of pain created anxiety around deadlines, social events, work, and commitments. Participants were not only managing pain itself, but also trying to anticipate whether pain would interfere with responsibilities they had already agreed to. Even careful planning could be undone by symptoms that appeared suddenly:

There's [an] amount of anxiety that [the unpredictability] causes me, more of looking at work deadlines or social deadlines and trying to plan: is that going to be a good or bad time? And sometimes, even if I plan things really well, it doesn't matter because the pain [is] just out of nowhere. And so I find that really taxing. And I also find it really hard to build momentum.

This account reveals that planning itself became labour. Participants were not only affected by pain, but by the uncertainty pain created before it arrived. Even careful planning could be undone, making it difficult to build momentum or trust future commitments. The anxiety described here is therefore not only fear of pain itself, but fear of pain disrupting obligations. Persistent pain created anticipatory labour: participants had

to think ahead, estimate risk, and prepare for the possibility that their bodies might not cooperate. Unpredictability therefore did not only disrupt plans after they were made; it shaped how participants approached planning itself.

This account also connects with de C Williams and McGrigor's (2024) distinction between self-regulation and social regulation of endometriosis pain. Participants self-regulated by monitoring symptoms, pacing, planning around cycles or flares, resting, using medication, and trying to anticipate bad days. However, because pain was unpredictable, self-regulation was never fully reliable. Participants also had to socially regulate pain by explaining cancellations, managing others' expectations, and trying to remain dependable despite fluctuating capacity. The present findings therefore show that unpredictability created both practical and social labour: participants had to manage their bodies and the meanings others attached to changed plans, absences, or reduced availability.

The unpredictability of pain affected participants' relationships because it made social participation difficult to sustain. Several participants described wanting to remain reliable friends, partners, family members, or colleagues, but pain could repeatedly interrupt plans. Others could interpret repeated cancellations as unreliability or lack of care. One participant noted that she was perceived by friends "as someone who wouldn't stick to plans or would never show up. Wouldn't be there when other people need help because I was actually home in pain."

This reflection highlights how symptoms could be misread as character. The participant's absence was not caused by lack of care, but by pain. Yet socially, repeated

absence could become interpreted as unreliability. Pain therefore affected relationships not only by limiting participation, but by changing how participants were perceived.

Over time, this repetition became socially difficult, not because participants lacked commitment, but because invisible and recurring pain did not fit easily with others' expectations of illness as temporary or clearly observable. Another participant described how repeated explanations could become exhausting for both herself and her friends:

So telling my friends I can't make it because I'm in pain and having that by-line all the time can sometimes be very exhausting for them. I know I was giving them fatigue to the point where, 'We've understood you last time, but it can't be the same thing this time'. And it's like, well, it is. It always is.

This extract captures the difficulty of living with recurring pain that is not always visible. For the participant, pain could be the same reason again and again, while for others, that repetition could become harder to accept. The social problem was therefore not only that pain interrupted plans, but that its ongoing nature challenged expectations that illness should be temporary, visible, and resolved. The participant's phrase, "it always is," captures the frustration of having a recurring explanation that others may eventually stop finding convincing. In this way, chronic pain created relational strain even when others were not intentionally dismissive.

This finding extends literature on stigma, disclosure, and the social regulation of endometriosis pain by showing how chronicity itself can become difficult for others to understand (Sims et al., 2021). Participants were not only managing isolated episodes of

pain; they were managing the social consequences of pain that repeatedly disrupted plans and required the same explanation over time (de C Williams & McGrigor, 2024). This suggests that invisible persistent pain can strain relationships not only through absence, but through the difficulty of making recurrent symptoms socially believable.

“You Look Fine”: Social Invisibility and Disclosure

Participants described pain as an internal experience that often had no visible marker. This invisibility shaped how others interpreted their capacity, reliability, and need for support. Unlike Theme 1, which focused on the medical legitimacy of invisible pain, this subtheme focuses on social legibility: how pain was understood or misunderstood in everyday life.

One participant described how looking well could override the reality of pain. In everyday settings, the absence of visible aids or obvious impairment made it easier for others to assume that she was coping:

You might be struggling and high pain on medication or whatever else you need to get through, but you can still walk around. There’s no wheelchair, there’s no walker, there’s no... People can’t see it. And if you look fine, then you’re OK.

This quote illustrates the gap between looking well and feeling unwell. Invisibility therefore made pain socially unstable: real to the participant, but easy for others to overlook or doubt. This shows how visibility shaped recognition. The participant’s pain had to compete with her appearance of functionality. Because others could not see the pain,

they could more easily assume that she was coping, exaggerating, or not in need of support.

Workplaces were another setting where participants had to manage the visibility of pain carefully. Disclosure could enable support or flexibility, but it could also expose participants to judgement about their reliability, capability, or professionalism. For this reason, participants often had to decide who needed to know, how much to explain, and what risks disclosure might create:

Within my role, there are very limited people [who] know because there is a massive difference between the right people knowing so that you're supported versus tell the world and run the risk of, 'Are you capable of your job? Oh, you've had another day off.' There has to be that fine line.

This extract reveals that disclosure was not simply openness, but a calculated decision shaped by the risk of judgement. The participant needed certain people to know in order to arrange support, but wider disclosure could threaten perceptions of competence and professional identity. Pain therefore had to be managed not only physically, but also reputationally. This is important because it shows how illness can enter the workplace even when symptoms are not directly visible. The participant was not only managing pain itself, but also managing how pain might be interpreted by others.

Participants described the burden of repeatedly explaining pain to others. Even ordinary social questions, such as being asked how they were, could become difficult

because the truthful answer rarely changed. One participant described becoming self-conscious about this repetition:

I'm very conscious that it's really hard because they say to you, 'How are you?' And then you, it's the truth, but you sound like a broken record because your answer is 'I'm tired, and I'm sore. I'm always tired, and I'm always sore. I'm good, but I'm tired, and sore.' And you become very conscious of that being your answer to everything.

This quote captures the fatigue of repeatedly narrating an unchanged reality. The participant's answer remained the same because her pain remained present, but repetition made her worry about how she sounded to others. This turned ordinary social exchanges into moments of self-monitoring. The burden was therefore not only explaining pain, but managing the social discomfort of having pain remain a constant part of everyday conversation.

These accounts align with research showing that endometriosis pain can be difficult to communicate and that women may struggle to find others who understand the extent of their symptoms (de C Williams & McGrigor, 2024). The present findings add depth by showing that invisibility did not simply mean that pain could not be seen. It meant that participants had to repeatedly translate an internal, embodied experience into language that others might understand. Even ordinary social exchanges could become sites of self-monitoring, because participants were aware that repeatedly saying they were tired, sore, or unwell could make them feel burdensome or repetitive. Invisibility therefore created a

communicative burden: participants had to make pain visible enough to be understood, but not so visible that it became socially uncomfortable.

The invisibility of pain shaped how participants moved through public spaces. Some participants experienced real physical limitations, yet these limitations were not always recognised because they did not match common assumptions about disability, age, or visible impairment. As a result, participants could be expected to function as able-bodied while living with pain that restricted mobility and access:

In New Zealand, we're not regarded as disabled people. So we're basically, you know, people that can live, work and live normally. So we're not entitled to any support from the government. We're not entitled to much access [with] the condition we have. Doing my grocery shopping, I can't park in the disabled parking spots, so I have to park where everybody parks, and that's a problem for me because I have nerve damage and my legs hurt and my body hurts. And when I walk, I crouch over with my back, and it's like watching an old lady walk to the supermarket. A lot of people look at my face, and they think, 'Oh, she's young and healthy, I wonder what she's doing.'

This account shows how invisible pain shaped access to public life. The participant experienced real mobility limitations, yet these were not easily recognised by others because her age and appearance did not match common expectations of disability. She was therefore expected to function as able-bodied while living with pain that restricted how she moved through social and physical environments. This extends the theme beyond

interpersonal misunderstanding, showing how invisibility could shape participants' felt access to ordinary spaces, supports, and accommodations. Sims et al. (2021) distinguish between enacted stigma, felt stigma, and self-stigma in endometriosis, but this account suggests that invisibility can also operate through everyday assumptions about who appears entitled to accommodation. "Looking fine" was therefore not merely a social misunderstanding; it could affect participants' ability to access practical support, move through public spaces, and have their limitations recognised as legitimate.

Performing Normality

Because pain was invisible and unpredictable, participants often described performing normality. This involved masking pain, appearing functional, over-explaining symptoms, pushing through, and controlling where pain could be shown. Participants did not perform normality because pain was minor; they performed it because the world around them continued to require participation.

One participant captured this dynamic directly: "People don't pretend to be sick, they pretend to be well." This phrase speaks to the social labour of invisible illness by reversing a common suspicion directed at people with unseen pain. Participants were not trying to appear more unwell than they were; they were often trying to appear less affected so they could remain acceptable, functional, and less burdensome. The performance of normality therefore protected participants socially while making their suffering harder to see. This created a paradox: the more successfully participants appeared to be functioning, the easier it became for others to underestimate the impact of pain. In this

way, masking helped participants participate, but it also reinforced the invisibility that made support harder to access.

This finding strongly aligns with literature on stigma and the social regulation of endometriosis pain. Sims et al. (2021) show that anticipated judgement or disbelief may shape whether people disclose symptoms or seek support, while de C Williams and McGrigor (2024) describe how women regulate pain both privately and socially. The present findings build on this by showing that masking was not simply concealment; it was a strategy for remaining acceptable, capable, and less exposed to judgement. Participants often performed wellness because social life, work, study, and relationships continued to require participation. This means that apparent functioning should not be read as evidence that pain was minor, but as evidence of the labour involved in making pain socially manageable.

Masking pain was exhausting. Because pain often occurred in public settings, participants described having to contain visible distress while continuing to appear composed. This meant that social participation required more than physical endurance; it also required emotional and bodily control. One participant described how much energy it took to keep functioning while trying not to show pain:

I mean, even with being in pain and having so many cramps, it's so tiring because I always have to put on a brave face. And just suffer through it because a lot of the time it just happens when I'm out, and that's so tiring. At the end of the day, I just come home exhausted and want to sleep.

This extract highlights that public functioning came at a cost. The participant was depleted not only by pain itself, but by the effort of appearing unaffected while pain was happening. Her exhaustion became visible only once she returned home, suggesting that masking shifted suffering out of public view rather than reducing it. In this way, appearing well did not mean that pain was manageable; it often meant that the participant had used significant energy to keep pain socially contained.

Participants pushed through pain to meet responsibilities or maintain a sense of life beyond illness. For some, continuing with ordinary activities was a way of resisting the narrowing of life around pain. However, this determination existed alongside real limitation, as one participant explained:

I don't let the pain affect me because ... I've had it so many years. ... You can't let it stop you. Sometimes, you know, it really does. But those are the worst days. But I don't let my pain stop me, because otherwise I won't get anything done. I want to have fun with my life.

This account reflects the tension between determination and limitation. The participant frames herself as refusing to let pain stop her, while acknowledging that pain sometimes does stop her. This is important because resilience should not be mistaken for the absence of impact. Her determination allowed her to keep participating in life, but it also required ongoing effort against a body that could still interrupt her plans. Masking and pushing through were therefore practical strategies for survival, but they did not erase the physical or emotional cost of pain.

Over-explaining was another form of performing normality. Participants sometimes spoke openly about endometriosis not only to share their experience, but to make absences, cancellations, or changes in behaviour more understandable to others. Disclosure could therefore function as a protective strategy, helping participants reduce judgement before it occurred.

I feel like I would talk about it all the time, and I did that as a way of protecting myself so that people understood when I would take time off work or when I would not be showing up how I always am. And I think that when I first came to terms with accepting the fact that I had it, I also felt like I had a responsibility to talk to people about it. So that they could understand. Not just for me but for other people.

This quote shows that disclosure was not simply openness. It was also a form of social management. By explaining her condition, the participant tried to make her behaviour legible and reduce the risk of being misread as unreliable, disengaged, or inconsistent. However, this placed responsibility on her to educate others and manage how her illness was interpreted. The phrase “not just for me but for other people” suggests that disclosure carried both personal and collective meaning, but it also shows the additional labour placed on participants to make endometriosis understandable in contexts where it was not already well recognised.

This account complicates disclosure as a simple choice between openness and concealment. Aerts et al. (2018) note that women may avoid informing employers about endometriosis because of possible consequences and because symptoms are private and

gendered. Participants in the present study showed that disclosure could also be used protectively: explaining endometriosis made absences, changes in functioning, or requests for flexibility more legible to others. However, this protective disclosure placed responsibility on participants to educate others and manage how their illness was interpreted. Disclosure therefore became another form of social labour, where participants had to decide how much to reveal in order to gain understanding without risking judgement, discomfort, or reduced credibility.

Pain was expressed differently across settings. Public spaces often required control, while home could become a place where participants no longer had to perform composure. One participant described this contrast between work and home:

And I can at work, because I mask it. And I can go to work, and I can have empathy for people at work. But then when I come home, the mask is off. And then suddenly, I'm like, 'I wish that I could mask it at home, but I feel safe.'

This sentiment underscores home as a space of relative safety. At work, the participant could continue performing care, empathy, and professional composure, but this required masking pain. At home, where she felt safer, the mask could come off. This does not mean that home was unaffected by pain; rather, it became the place where pain and exhaustion were more fully expressed. The quote therefore shows how masking redistributed pain across settings. Public life required containment, while private life absorbed the emotional and physical aftermath.

For other participants, public expressions of pain were shaped by embarrassment and fear of being watched or judged. One participant described how difficult it was to show pain in a university setting:

It feels embarrassing in public at uni and stuff. I don't want to make a scene because then people will look over at me and be like, 'Oh, there's nothing wrong, she's fine. What's wrong with her? She's so weird', you know, like overexaggerating and stuff. So dramatic. And it's just so hard to like show your pain when you're in pain.

This extract demonstrates how visible expressions of pain could feel socially risky. The participant anticipated being judged as “weird,” “overexaggerating,” or “dramatic,” particularly because others could not see what was happening inside her body. Her account shows that pain was not only difficult to endure, but difficult to display. Together, these accounts show that pain was not expressed uniformly. It was shaped by setting, safety, embarrassment, surveillance, and social expectations. Performing normality allowed participants to remain socially acceptable, but it also concealed suffering and made the labour of living with pain harder for others to recognise.

Organising Life Around Pain

Persistent pain shaped the organisation of work, study, relationships, intimacy, hobbies, rest, and energy. Participants did not simply miss out on isolated activities; they reorganised their lives around what their bodies allowed. This reorganisation was practical, social, and emotional.

However, the impact of pain was not always visible as absence from work. For some participants, pain had already been built into the way they structured employment, making its effects harder to explain or measure:

I had a question there at the pain clinic saying, how does your pain impact your life, your ability to work? And I was like, I don't know how to answer this because I've made my work flexible to adapt my pain to my work, so I don't get taken away from work because I have to work because we live in a society where you have to work. So it's really hard to answer things like that because you have to navigate things realistically, but also in creative ways.

This account highlights that the impact of pain could be hidden by adaptation. Because the participant had already restructured work around pain, it became difficult to describe how much pain affected her. Functioning, in this context, was not the absence of limitation but evidence of continuous adjustment. The participant's need to "navigate things realistically, but also in creative ways" shows that maintaining employment required planning, flexibility, and compromise. Pain therefore shaped work, even when it did not entirely remove the participant from it.

This finding aligns with literature showing that endometriosis-related symptoms affect employment, education, social life, daily activities, and quality of life (Aerts et al., 2018; de C Williams et al., 2026; Tewhaiti-Smith et al., 2022). The present study extends this literature by showing that the impact of pain was sometimes hidden by adaptation. Participants were not always absent from work or study; instead, they restructured work,

routines, expectations, and energy use around pain. This means that conventional measures of functioning may underestimate the impact of persistent pain when people have already reorganised their lives to remain employed, studying, parenting, or socially present. Adaptation therefore made life possible, but it could also make the extent of disruption harder for others to see.

Work involved social negotiation. Participants had to manage not only symptoms but also how colleagues interpreted fluctuating capacity. One participant described the difficulty of needing support on some days while still holding authority and responsibility on others:

It's really hard when your colleagues and you are kind of on the same level. But I don't want there to be a sense that I'm getting differential treatment because I leave early or go to appointments, I have more sick days etcetera. And to on one day, be saying I need help, I can't manage, and then the next day to be like leading a meeting and delegating to other people. It just does quite funny things to the dynamic, like kind of social workplace dynamics.

This extends existing research on work and education disruption by showing that pain affected not only whether participants could work, but how they were positioned within workplace relationships, authority, fairness, and competence. Fluctuating capacity was difficult to explain in workplaces organised around stable performance and reliability. This also connects with Aerts et al. (2018), who note that women may avoid disclosing endometriosis symptoms or diagnosis to employers because of possible consequences

and because symptoms are private and gendered. The present findings extend this by showing that disclosure was not simply about revealing illness, but about managing professional credibility, perceived reliability, and access to support.

Education was similarly disrupted. Pain affected attendance, concentration, and the ability to remain engaged in study. For one participant, pain-related disruption accumulated until continuing university became impossible:

And so that thing just like snowballed into me not attending uni, dropping classes, not even going to the few classes that I was. My friends had to look after me. I was sleeping in people's rooms because I couldn't be on my own, and it was no good. So I ended up going home early, and so I didn't finish my first year of uni.

The word "snowballed" is important because it shows how pain-related disruption accumulated over time. Missing classes, dropping papers, needing friends' support, and being unable to stay alone built into a larger loss of educational participation. Pain therefore affected life trajectories, not only daily activities. In this account, study was not simply interrupted by symptoms; the participant's whole capacity to remain in the university environment was undermined.

Pain shaped friendships and social participation. Participants described the difficulty of repeatedly cancelling plans or withdrawing from social life, while understanding how this might affect others. Another participant explained that "there have been some friendships that have changed. And you know what, I can put myself in their

shoes. And if someone bailed on me every time I hung out, yeah, I'd probably stop inviting them too."

This perspective highlights the tension between the guilt and empathy participants carried. She understood why friends might withdraw, even when cancellations were due to pain rather than a lack of care. Social loss was therefore compounded by the participant's awareness of how pain affected others. It shows how chronic pain can become socially difficult to sustain: repeated cancellations may be reasonable from the perspective of pain, but still difficult for others to understand or accommodate over time.

Pain shaped intimacy and close relationships. For some participants, intimacy became another area of life that had to be negotiated around symptoms, uncertainty, vulnerability, and disclosure. Pain could affect sexual confidence, relationship formation, and the ability to be physically close without fear of discomfort or misunderstanding:

Another big one for me too is painful sex. So, you know that intimacy is such an important part of being human. And when you're in pain, and you start getting pain, you're missing out on that part of your life.

This quote demonstrates that pain affected participation in both intimate and public life. Sexual pain was not only a physical symptom; it shaped closeness, confidence, vulnerability, and the ability to participate in a valued part of human connection. This participant's phrase "missing out on that part of your life" highlights that intimacy was experienced as a meaningful dimension of wellbeing, not as a secondary or minor concern.

This extends the social impact of persistent pain into private relationships, where pain could affect both the body and the possibility of connection.

The organisation of life around pain also extended beyond work and study into relationships, intimacy, social participation, hobbies, and rest. This aligns with research showing that endometriosis can affect relationships, sexual wellbeing, social life, and emotional wellbeing, not only physical functioning (Aerts et al., 2018; de C Williams et al., 2026). The present findings add nuance by showing that these areas were not always separately disrupted; they were reorganised together through limited energy, fear of flares, medication use, fatigue, and the need to prioritise what could be managed. Pain therefore shaped the architecture of everyday life, influencing how participants distributed energy, protected relationships, and decided what parts of life could still be maintained.

Participants had to ration energy. Everyday decisions involved weighing the value of an activity against the likely physical and emotional cost. One participant described this as a process of deciding where limited energy should go:

I can't change it. I can only control what's in my control, and then the things that are outside of my control, I have to decide what I put the energy into. If I'm sore and there is a very important event coming up, it is a balance. If I'm sore and it's just to catch up with mates, I know I can bail out. I feel bad, but I know I can bail out. But it's about where do I put my energy correctly into what's, like I said, in my control versus out of my control.

This reflection illuminates the participant's perception that participation became a triage process. Participants had to decide which activities were worth the physical cost and which could be cancelled, postponed, or avoided. Energy was therefore not treated as an ordinary resource, but as something limited, uncertain, and requiring careful allocation. The participant's distinction between important events and casual social plans shows how pain reorganised priorities. This was not simply avoidance; it was an attempt to preserve capacity in a body that could not be relied on to support everything.

Pain days and good days were experienced as markedly different. Participants described pain days as periods to get through, while good days became opportunities to reconnect with activity, pleasure, and others:

But when I'm in pain ... I'm just not happy. Like I'm not texting my friends. I'm not like calling people and talking to people. I'm not even like enjoying relaxing because it's not relaxing. It's just sad. It's just like, get through it. Get through it and make it back to a good day. And then on the good day, I'll be so happy again, and I'll feel so good, and I'll go and do all these fun things I want to do. So yeah, it's such a huge difference, definitely.

This extract captures the contrast between enduring pain and participating in life. Pain days were not restful; they were time to survive. Even relaxing was not experienced as restorative because pain shaped the participant's emotional state, social connection, and ability to enjoy rest. Good days, by contrast, became moments when life reopened and the

participant could reconnect with activities and people. This contrast shows how persistent pain organised time itself, dividing life into periods of endurance and periods of possibility.

Overall, this theme shows that persistent pain shaped the external organisation of life through unpredictability, invisibility, disclosure, masking, social expectations, work, study, relationships, intimacy, and limited energy. The findings align with existing literature showing that endometriosis-related pain affects daily life, employment, education, relationships, social participation, and quality of life. However, they extend this literature by showing that these impacts were not explained by pain intensity alone. They were shaped by the social work required to live with a body that could not be scheduled and pain that could not always be seen. Participants had to plan around uncertainty, explain symptoms selectively, manage others' interpretations, perform normality, and reorganise life around fluctuating capacity. In this sense, pain was not only privately endured; it was socially managed. Having examined how participants organised their external lives around unpredictable and invisible pain, the next theme turns inward to consider how persistent pain was carried psychologically through distress, self-doubt, guilt, rumination, identity disruption, acceptance, and self-compassion.

Theme 4: Carrying Pain Internally: Distress, Self-Doubt, and Self-Compassion

This theme examines the psychological and internal impacts of endometriosis-related persistent pain. It explores how pain shaped participants' emotional wellbeing, self-trust, identity, guilt, rumination, mood, and attempts to rebuild a liveable sense of self. Participants had to negotiate doubt within themselves: whether pain was severe

enough, whether rest or medication was justified, whether they were being dramatic, and whether they were failing to cope. In this way, external invalidation could become part of the internal psychological burden of pain.

Participants' accounts show that pain affected how they understood themselves. It generated grief for the person they used to be, guilt about the impact of pain on others, self-doubt about whether pain was "bad enough," and distress when pain felt endless. At the same time, participants described learning self-compassion, acceptance, and resilience. These processes were not linear or simple. Acceptance could coexist with anger, grief, hopelessness, and determination. Resilience could be meaningful, but it could also be something participants felt forced into by the absence of easier options.

This theme is organised into four subthemes: Pain and the disrupted self; Guilt, burden, and self-doubt; Rumination, mood, and psychological distress; and Rebuilding through self-compassion and acceptance.

Pain and the Disrupted Self

Persistent pain disrupted participants' sense of who they were and what their lives would look like. Diagnosis could provide validation, but it also required participants to confront chronicity: the possibility that pain might not have a clear endpoint. This changed the temporal meaning of illness. Pain was not simply something to recover from, but something participants had to imagine living with.

For some participants, this realisation was overwhelming because it changed how they understood the future. Pain became not only a present experience, but something that could extend across the life course:

Because there were so many dimensions to what was going on and that it's just confusing and overwhelming because, yeah, you're dealing with the fact that you've got a chronic pain disease for the rest of your life, there is no cure.

In this context, the data shows that participants were not only processing pain in the present; they were processing the future implied by pain. The phrase “for the rest of your life” carries the weight of chronicity and suggests an altered life course. Pain therefore became an existential issue, shaping not only symptoms but how participants imagined the future.

This finding aligns with qualitative literature showing that endometriosis-related pain can affect women’s sense of self, imagined future, freedom, and relationship with their bodies (de C Williams & McGrigor, 2024). The present findings extend this literature by showing how diagnosis could introduce a new temporal burden. While diagnosis validated pain, it also required participants to imagine pain as something that might continue indefinitely. This shifted pain from an acute or temporary problem into a long-term condition that had to be incorporated into future planning, identity, and expectations of the body. The psychological impact of pain therefore included not only distress about current symptoms, but also the emotional work of imagining a future with persistent uncertainty.

Participants grieved the healthy self and the access to the world that came with that self. This grief was not always immediately recognisable as grief; it could first appear as anger, resentment, or comparison with people whose bodies seemed more reliable:

And a lot of times I used to hate people [who] were healthy, sit at home and do nothing. And I used to think in my head, I hate these people. They just sit at home and waste the health they have, but I realised it was because I was grieving. And putting to death, I suppose, the healthy life that I did live and the amount of access I had to the world as a healthy person.

This account frames grief as a response to lost access. The participant was not simply envious of other people's health; she was grieving the version of herself who could move through the world more freely. Persistent pain therefore created a form of loss that was difficult to recognise because the participant was still physically present, but living with a body that no longer offered the same freedom.

Pain affected valued roles, including parenting. For participants with caring responsibilities, pain could interfere not only with activity, but with the kind of parent, partner, or family member they wanted to be:

But then I beat myself up because I cannot go and do things with the kids that I would like to at certain times, and then that impacts my self-worth as a parent. I don't want to be the mum that's stuck on the couch in pain, but I am sometimes. And I just have to accept that. And it's like the grief that surrounds it. I can't... I can't do what I want to do.

This account reveals that grief was tied to self-expectation. The participant was not only upset because pain limited activity; she was grieving the gap between the parent she wanted to be and the parent pain sometimes allowed her to be. Persistent pain therefore affected identity by interfering with roles through which participants understood themselves as caring, capable, or reliable.

This account connects with Dowding et al. (2024), who found that women sought psychological therapy not only for pain, but also for grief, uncertainty, loss of identity and ability, trauma, anxiety, depression, and adjustment to chronic illness. Participants' accounts in the present study show why grief was such an important part of the internal burden of pain. They were not only grieving specific activities or opportunities, but also a previous relationship with the body and a former sense of what life could be. This extends existing literature by showing that grief in endometriosis-related persistent pain can be diffuse and ongoing: grief for reliable functioning, ordinary participation, emotional stability, and a self that did not have to constantly negotiate pain.

Some participants described trying to rebuild an identity in which endometriosis and pain were acknowledged but did not define the whole person. This involved neither denying the illness nor allowing it to become the only way they understood themselves:

It's sometimes a big part of my life, other times it's a really small part of my life, depending on what day it is and the situation and stuff. So I think that it's definitely changed the way that I view myself and my identity. But I'm trying to step a little bit

out of that now and just find ways to be more of a whole person. And that's just part of me rather than who I am. I am me, and I have endo.

This quote captures the work of identity reconstruction. The participant does not deny the significance of endometriosis, but she resists being reduced to it. The statement “I am me, and I have endo” suggests an attempt to integrate pain into identity without allowing it to consume the whole self.

Together, these accounts show that persistent pain disrupted identity by changing participants’ relationships with their bodies, roles, and futures. Chronicity, grief, and altered capacity shaped how participants understood themselves, while some also worked to rebuild an identity that acknowledged pain without being defined by it. This subtheme therefore shows that persistent pain affected not only what participants could do, but who they felt able to be.

Guilt, Burden, and Self-Doubt

Persistent pain carried a significant burden of guilt. Participants felt guilty not only for being in pain, but for the impact their pain had on parents, partners, friends, children, and others close to them. One participant describes trying to contain her pain in order to protect others from its emotional weight:

I've always thought of it as a burden, having this condition, having this diagnosis.

And I'm like, I don't want to give this burden to someone else. So which is why I've never openly talked about it. I was like, it's OK if I deal with the physical aspect or

the mental aspect of what I've got by myself. But I'm dragging my parents down with me.

This extract sheds light on how pain became relational. The participant was not only carrying physical and psychological distress; she was also trying to manage the perceived burden placed on others. Her silence was not caused by a lack of need, but by fear of transferring emotional weight onto her family. Guilt therefore intensified isolation by making disclosure itself feel like another burden placed on loved ones. Pain became something to manage privately, even when privacy increased emotional strain.

These accounts align with literature showing that endometriosis-related pain affects relationships, social wellbeing, and emotional functioning, but they add detail about how those effects became internalised. Participants did not only experience practical dependency; they interpreted dependency through guilt, burden, and fear of letting others down. This suggests that relational impacts of pain were carried psychologically as well as socially. The burden of pain therefore extended beyond symptoms and tasks into participants' sense of whether they were asking too much, failing others, or becoming difficult to love or support.

Guilt could become self-blame. When treatment advice emphasised lifestyle management, participants sometimes felt responsible for preventing flare-ups. This created pressure to constantly monitor behaviour, routines, and choices:

Because the treatment plan for endo is surgery and lifestyle. So in my life, I spend a lot of time thinking about what to do to prevent flare-ups. Daily, and if not hourly. So it's hard not to sit in a space of this is my fault.

This account highlights how self-management can become psychologically burdensome. Although lifestyle strategies may offer some sense of agency, they can also imply that flare-ups are preventable if the person manages herself correctly. When pain continued despite effort, responsibility could turn inward as blame. The participant's phrase "daily, and if not hourly" shows the intensity of this monitoring. Pain was therefore not only something she experienced, but something she felt responsible for preventing, explaining, and managing correctly.

Participants doubted their own pain. Because pain fluctuated, its absence could make earlier pain harder to believe. This meant that self-doubt was produced not only by other people's dismissal but also by the changing nature of pain itself:

Because it flares. So because right now, right now I'm fine. I'm in no pain at all. Fine. So then I'll make a doctor's appointment, then I'll cancel it. I'll make it when I'm in pain, and then I'll cancel it because, oh no, I'm fine. So it's this constant cycle, and then I have to try and remind myself.

This quote demonstrates how unpredictable pain affected self-trust. When pain disappeared, it could undermine the urgency felt during a flare. The participant had to "remind" herself because the absence of pain made its earlier severity harder to hold onto as legitimate. This shows that pain unpredictability did not only affect planning or care-

seeking; it also affected participants' ability to believe themselves across changing bodily states. The participant had to remember and re-believe her own pain, even when her current body no longer confirmed it.

Participants also described internal "battlefields" around whether pain was severe enough to justify rest, medication, cancellation, or help-seeking. These internal negotiations show that the burden of legitimacy discussed in Theme 1 could become internalised. Participants did not only have to prove pain to others; they also had to prove it to themselves. Guilt, burden, and self-doubt therefore formed part of the internal labour of living with persistent pain, as participants tried to balance their own needs against expectations of responsibility, endurance, and care for others.

This finding links back to literature on dismissal, invalidation, and epistemic injustice by showing how external disbelief can become internal self-doubt. Carel and Kidd's (2014) concept of epistemic injustice is useful here because participants' testimony about pain was not always treated as credible within healthcare and social contexts. Over time, this could shape how participants evaluated themselves. In the present study, self-doubt was not simply an individual cognitive error or lack of confidence; it was produced through repeated experiences in which pain had been normalised, minimised, psychologised, or made difficult to prove. This suggests that internal doubt was socially and clinically formed before it became psychologically carried. Self-doubt was therefore socially produced before it was internally carried.

Together, these accounts show that guilt, burden, and self-doubt were not separate from pain, but part of how persistent pain was internally carried. Participants tried to protect others, manage themselves correctly, and decide whether their pain was serious enough to justify care or rest. In this way, the struggle for legitimacy described in Theme 1 became internalised, as participants not only defended pain to others, but also had to keep convincing themselves that their pain was real and worthy of response.

Rumination, Mood, and Psychological Distress

Persistent pain had significant effects on mental health. Participants described rumination, catastrophising, anxiety, panic, depression, sleep disturbance, suicidal thoughts, and changes in mood. These experiences were not separate from pain, nor were they evidence that pain was “in the head.” Rather, participants’ accounts show an interactive relationship in which pain affected mental wellbeing, while distress, tension, fear, and rumination could also shape how pain was experienced and endured.

One way this relationship appeared was through cycles of emotional suppression, bodily tension, and increased pain. Participants described how thoughts that were held internally could become physically embodied, intensifying pain and worry:

And so because I was simmering in these thoughts and not really letting it out, and it made me physically tense up. And so when I was tense, that would affect my pain levels. And I would be thinking, ‘Why am I in so much pain?’ And I would start the whole cycle over again.

This quote captures the circular relationship between pain and distress. Thoughts were not separate from the body; they contributed to tension, which then intensified pain and produced further worry. The participant's account therefore illustrates a biopsychosocial loop in which emotional suppression, bodily tension, pain, and rumination reinforced one another. Importantly, this does not make the pain imaginary. Rather, it shows how psychological distress became part of the embodied experience of persistent pain.

This finding aligns with Kalfas et al. (2022), who identified rumination, catastrophising, anxiety, depression, stress, acceptance, and self-efficacy as relevant psychosocial factors associated with pain and health-related quality of life in endometriosis. However, participants' accounts add important context to these associations. Rumination was not described only as unhelpful thinking; it often functioned as an attempt to make sense of unpredictable pain, identify triggers, prepare for future flares, or regain control in a situation that felt uncertain. This means that rumination should be interpreted carefully. In this study, repetitive thinking was not evidence that pain was psychologically caused, but part of the work of living with pain that was persistent, difficult to explain, and not always adequately supported.

Participants described being unprepared for the mental health impact of living with pain over time. In some cases, this distress was later framed by clinicians as understandable, but participants had not necessarily been supported before it became severe.

He said, 'I was expecting this to happen.' And I said, 'Why?' He said, 'Because you've been dealing with this from such a young age, and it went undiagnosed for so long, and you just kept getting told, it'll settle, you'll get better, you know, just try this pain med and whatnot. It's been affecting you mentally as well as physically.'

This interaction suggests that psychological distress was a predictable consequence of prolonged pain and delayed recognition, yet it had not necessarily been addressed proactively. The participant's mental health difficulties were not presented as separate from endometriosis, but as something that developed through years of pain, uncertainty, and repeated reassurance that symptoms would settle. This highlights the need to understand mental wellbeing as part of pain care from the beginning, rather than only responding once distress becomes severe.

Several participants described depression and withdrawal during periods of severe or ongoing pain. These accounts show that pain affected mental wellbeing not only through physical suffering, but by narrowing daily life, reducing connection, and limiting ordinary sources of meaning.

Before I had any surgeries, when it was just pain every day for like months and months. That was terrible. My mental health was really bad. I never left the house, I never saw anyone. ... I think it affected my mental health a lot, it was so, so terrible. So yeah, dark times.

This extract links daily pain, isolation, and mental health decline. The participant's world narrowed as pain continued, with social contact, movement, and routine all

reduced. Persistent pain therefore affected mental wellbeing not only because it was physically severe, but because it limited access to the activities and relationships that might otherwise support coping. The phrase “dark times” captures the emotional weight of living in a period where pain had become both constant and isolating.

These accounts are consistent with literature linking endometriosis-related pain with psychological distress and poorer quality of life (Kalfas et al., 2022; van Niekerk et al., 2022a). The present findings support this relationship but also clarify its meaning. Participants’ distress was not presented as separate from pain, nor as evidence that pain was “in the mind.” Rather, distress emerged through the cumulative effects of severe symptoms, uncertainty, repeated dismissal, disrupted participation, fear of recurrence, and limited control. This supports a biopsychosocial understanding of persistent pain in which emotional distress is part of the lived pain experience, not a competing explanation for it.

For some participants, distress became severe enough to include suicidal thoughts. These accounts need to be understood carefully. Participants often framed these thoughts not as a simple desire not to live, but as desperation for pain to stop when other forms of relief felt unavailable:

And so when I say those things or when I think those things, it's not because I'd want to stop living. It's because I just want the pain to stop, and if it means not breathing and the pain is gone, to me that's a dream.

This quote locates suicidal thoughts within the experience of relentless pain. The participant distinguishes between wanting life to end and wanting pain to stop, showing how unmanaged pain could make non-existence appear desirable only because it represented relief. This does not reduce the seriousness of suicidal thoughts; rather, it highlights the urgency of treating psychological distress as part of pain care. Pain relief, emotional support, and timely intervention are therefore not secondary concerns, but central to safety and wellbeing.

This finding adds depth to the literature on psychological distress in endometriosis by showing that distress can become acute when severe pain, limited relief, uncertainty, and lack of support converge (Dowding et al., 2024; Kalfas et al., 2022). It also reinforces the need to treat mental wellbeing as part of pain care, rather than as separate from the physical realities of endometriosis-related persistent pain.

Rumination was common during pain episodes. Participants described how pain could make the future feel frighteningly closed, as present suffering became imagined as permanent:

The cycle of thoughts in my pain space is very much the negative thoughts, like, 'Will this ever end? This won't end, this is the rest of my life.' And then very quickly cycles into, 'I don't know if I want to do the rest of my life, if this is what the rest of my life looks like.' So that can be like the dark path that my brain cycles through a lot with that.

This extract reveals how pain changed the participant's relationship to the future. During pain episodes, the future could collapse into an extension of the present: if pain felt endless now, life itself could begin to feel unendurable. Rumination therefore intensified distress by transforming temporary or episodic flares into imagined permanence. The participant's phrase "the dark path" also suggests that these thoughts were not isolated worries, but a repeated mental route that pain made easier to enter.

Catastrophic thinking appeared in participants' accounts, particularly when mental health was already poor. Rather than treating this as irrational thinking, participants' accounts show that catastrophic interpretations emerged in the context of severe, unpredictable, and difficult-to-explain pain:

If I'm having a bad mental health day, sometimes I can start going, 'Oh maybe it's not [endometriosis]. Maybe it's like worse. Maybe this is like I've got cancer. Or maybe I've got a stomach bug coming that's really awful gastroenteritis. Maybe you know, this?' Yeah. So if I'm in a better mental health space, I'm more able to just be mindful about it and be realistic and rational about it. But if I'm not in good mental health, it's just my mind starts spiralling.

This quote is important because it explains that pain interpretation was shaped by emotional state. When the participant felt more regulated, she could understand pain as part of her condition; when she was distressed, pain became more threatening and uncertain. This suggests that catastrophising was not simply irrational thinking, but a response to living with pain that could be severe, unpredictable, and difficult to explain.

The participant's awareness of this process is also important. She recognised that her ability to interpret pain depended on her mental health, showing the close interaction between cognition, emotion, and bodily experience.

Pain affected emotional regulation and mood. Participants described having less emotional capacity when pain was high, which could affect how they responded to everyday frustrations or relational demands. One participant reflected, "That's just one of those things that people with chronic pain [do] ... people get agitated when you have high pain because your cup is overflowing, your window of tolerance is gone."

This account reframes irritability as depletion rather than personality. Pain reduced the participant's emotional capacity, leaving less room to manage everyday stress, frustration, or relational demands. The image of an overflowing cup suggests that emotional reactions were not separate from pain, but emerged when pain had already consumed the participant's available resources. This helps explain why chronic pain can affect mood and relationships even when participants are trying to remain caring and controlled.

Some participants described feeling like different versions of themselves depending on whether they were in pain. Pain could shape mood, openness, kindness, irritability, and social capacity, making it difficult to separate the self from the effects of symptoms:

Sometimes I'm grumpy or short with people, or sometimes I can be really kind and friendly and open to conversations. It actually does mess with my emotions as well. So it's really hard to feel like, well, this is my authentic self because my authentic

self is actually dictated by my condition, my pain. And then after my pain, my moods.

This reflection deepens the identity disruption described earlier in the theme. The participant was not only distressed by pain; she was unsettled by the way pain shaped how she related to others. Persistent pain therefore raised questions about which version of the self felt real when mood, energy, and openness fluctuated with symptoms. This shows that psychological distress was not limited to anxiety or depression, but also affected self-perception and the participant's sense of authenticity.

This finding extends existing literature by showing that psychological distress was also experienced as disruption to authenticity. While research often discusses anxiety, depression, stress, or reduced quality of life, participants' accounts show that pain could disturb the relationship between mood, behaviour, and identity. The participant's uncertainty about her "authentic self" suggests that pain did not only change how she felt; it changed how she recognised herself in relation to others. This adds nuance to psychosocial literature by showing that the internal burden of endometriosis-related persistent pain includes questions of personhood, emotional consistency, and self-recognition, not only symptom-related distress.

Together, these accounts show that rumination, mood changes, and psychological distress were deeply intertwined with persistent pain. Participants' distress was not separate from the body, nor did it make pain less real. Instead, pain and distress interacted through cycles of tension, withdrawal, fear, catastrophic interpretation, emotional

depletion, and altered self-perception. This subtheme therefore supports a biopsychosocial understanding of endometriosis-related persistent pain, in which mental wellbeing is part of pain experience and pain care.

Rebuilding Through Self-Compassion and Acceptance

Despite the psychological burden of persistent pain, participants also described ways of rebuilding a liveable relationship with themselves. This involved self-compassion, acceptance, boundary-setting, reframing, and resilience. These processes were not simple solutions and did not remove pain. Rather, they helped participants reduce shame, soften self-blame, and create a life less wholly governed by pain.

Self-compassion often involved changing internal dialogue, especially around rest and productivity. For some participants, resting was difficult because it conflicted with internalised expectations about usefulness, discipline, and worth. One participant described having to actively challenge these messages:

At first I felt guilty. I would sit there and go, ‘Oh, I should be doing something.’ And I just feel really antsy, like there would always be my mum’s voice, ‘Oh, you’re sitting around again being lazy.’ But then I would always tell myself, ‘No, you’re not being lazy. You’re actually resting, and resting is a productive action as well’, and so I always mixed up being worthwhile with being productive.

This quote reveals self-compassion as a learned counter-narrative. The participant had to challenge internalised messages that equated rest with laziness and productivity with worth. Reframing rest as productive care helped reduce the shame attached to

stopping. This matters because pain often forced participants to rest, but rest could only become restorative when it was no longer interpreted as personal failure.

This finding aligns with research identifying self-compassion as a relevant process in endometriosis-related wellbeing. Van Niekerk et al. (2022b) found that lower self-compassion was associated with greater psychological distress, longer diagnostic delay, and greater symptom burden, while Skinner and Kuijer (2025) describe self-compassion as a possible protective resource for psychological wellbeing and health-related quality of life. Participants' accounts in the present study give qualitative meaning to these findings. Self-compassion was not an abstract trait; it was practised through small internal shifts, such as allowing rest, reducing self-blame, challenging productivity-based worth, and treating the body with less hostility. This suggests that self-compassion may matter because it changes the internal conditions under which persistent pain is carried.

Participants described reducing pressure to find a cure or return to an ideal version of life. This did not mean giving up on wellbeing, but it involved loosening expectations that life could only be acceptable if pain disappeared completely. One participant described how reducing this pressure created more emotional space:

The other thing that I try and do is not put too much pressure on myself about finding a cure or being healed, or it's just, if my life looks like I work 40 hours a week and I can only manage a phone call with my friends, then that's OK. And taking that pressure away from yourself allows a bit of space for you to just have your moment.

This extract emphasises that acceptance involved changing the standard by which life was judged. Rather than measuring herself against a pain-free ideal, the participant made room for a life organised around current capacity. This did not remove pain, but it reduced the additional suffering created by constant self-comparison and pressure to be healed. Acceptance therefore created space to live within limitation without interpreting every limitation as failure.

Acceptance was complicated. For some participants, it involved recognising that pain was part of their life and their embodied reality. This did not necessarily mean seeing pain as fair or desirable, but acknowledging that it had become part of the self they had to live with:

It's part of me now. I can't change that. It's part of, you know, I've dealt with it for like a decade of my life now almost. So it's fully ingrained in my whole system and in my being. And so it comes as a package deal with me.

This statement shows acceptance as integration. The participant does not describe pain as the whole self, but as something inseparable from her embodied reality. The phrase “package deal” suggests that acceptance involved recognising pain as part of life while continuing to claim personhood beyond it. Pain was not erased or welcomed, but incorporated into how the participant understood herself.

This finding also connects with research suggesting that acceptance, self-efficacy, perceived control, and psychological flexibility are relevant to functioning and quality of life in endometriosis-related pain (Åkerblom et al., 2026; Kalfas et al., 2022). However,

participants' accounts show that acceptance should not be romanticised or treated as simple adjustment. Acceptance did not mean that pain became acceptable, nor that participants stopped wanting relief or better care. Rather, acceptance was often a difficult and ongoing process of reducing self-blame, living with uncertainty, and finding ways to continue valued activities when pain remained present. The present findings therefore extend the literature by showing acceptance as a negotiated process shaped by available care, support, exhaustion, hope, and the absence of easy cures.

However, acceptance could also feel close to hopelessness. Some participants described continuing because they had to, not because they had found peace with pain. This distinction is important because acceptance can emerge from self-compassion, but it can also emerge from exhaustion and limited options:

I think it would be fair to say all of us have reached that point at some point in time, where you just go, you just don't bother anymore. Like you just push through it. You know there's nothing for you. There is no magic pill or magic injection that you can have.

The significance of this quote lies in its ability to prevent acceptance from being romanticised. "Not bothering anymore" may look like acceptance, but it can also reflect the absence of effective options. For some participants, accepting pain meant recognising the limits of available treatment and continuing anyway. This matters because acceptance should not be treated as a simple psychological achievement when it may also be shaped

by repeated disappointment, inadequate relief, and the need to keep functioning despite pain.

Living well therefore requires redefining what a good life could look like with pain present. Participants sometimes described small activities as meaningful because pain had made them uncertain or difficult. One participant described living well through everyday acts of participation and enjoyment:

I'm a person with this condition living life the best way that I can, even if it's getting up, even if it's being able to make a cup of tea or going for a little walk. Living well means being able to do things like that, that I appreciate and enjoy.

This extract demonstrates how participants recalibrated the meaning of a good life. Small acts such as making tea or going for a walk became meaningful because pain had made them uncertain. Living well was therefore not defined by the absence of pain, but by the ability to find value, pleasure, and agency within constraint. This reframing allowed participants to recognise moments of wellbeing without requiring life to return to an earlier, pain-free ideal.

Resilience was also present, but it was complex. Participants sometimes saw themselves as strong, stubborn, or determined, but this should not become a moral expectation. One participant recognised her own persistence while also resisting the idea that everyone should respond to pain in the same way:

And I think I've made it work despite the pain, the setbacks being dismissed, not being validated, being ignored. You know, I think I made it work despite that, but that's just because that's me, and everybody's experience is going to be so different.

This quote frames resilience as personal rather than prescriptive. The participant recognises her own determination while also acknowledging that everyone's experience is different. This prevents resilience from becoming another standard against which people with persistent pain are judged. Living with persistent pain required different forms of meaning-making, and there was no single correct way to accept, endure, or rebuild life around pain.

Participants' accounts also complicate simple celebrations of resilience. Resilience could be meaningful when it reflected self-knowledge, boundary-setting, and renewed agency, but it could also feel like something participants were forced to develop because pain, waiting, and limited treatment options left them with few alternatives. This distinction matters because framing people with persistent pain as resilient can unintentionally obscure the systems and relationships that make resilience necessary. In the present study, resilience was therefore not only an individual strength; it was also a response to conditions in which participants had to keep going while still seeking recognition, relief, and support.

Taken together, this subtheme shows that self-compassion and acceptance were important parts of how participants rebuilt a relationship with themselves. However, these processes did not erase pain, remove the need for care, or make suffering acceptable.

Rather, they helped participants reduce self-blame, soften shame, recognise limits, and create meaning within constrained circumstances.

Overall, this theme shows that endometriosis-related persistent pain was carried internally through grief, guilt, self-doubt, rumination, distress, altered identity, and attempts to rebuild self-compassion and acceptance. The findings align with existing literature showing that endometriosis-related pain is associated with psychological distress, reduced quality of life, identity disruption, rumination, acceptance, and self-compassion. However, they extend this literature by showing how these internal processes were produced through the interaction of embodied pain, social invalidation, healthcare uncertainty, disrupted participation, and personal meaning-making. Participants did not carry distress because pain was unreal or merely psychological; they carried distress because pain was persistent, unpredictable, often difficult to legitimise, and not always relieved by diagnosis or treatment. Self-doubt and rumination were therefore not isolated cognitive processes, but ways of living with pain that repeatedly disrupted trust, agency, relationships, and the imagined future. At the same time, participants' accounts of self-compassion and acceptance show that living with persistent pain involved active psychological work to soften blame, preserve personhood, and make life more liveable. Having examined how pain was internally carried, the final theme considers what helped reduce this burden through validation, support, pain relief, mental health care, and whole-person approaches to care.

Theme 5: Making Pain Liveable: Support, Relief, and Whole-Person Care

This final theme examines what reduced the psychosocial burden of endometriosis-related persistent pain, even when pain did not disappear. Across participants' accounts, making pain liveable did not usually mean finding a cure or returning to a pain-free life. Rather, it meant having pain believed, supported, relieved, understood, and managed in ways that allowed participants to remain connected to themselves and others. This theme therefore brings together the central concerns of the previous themes. If participants struggled to legitimise pain, waited in pain, organised life around pain, and carried pain psychologically, this theme shows what helped reduce that burden. In this way, the theme moves from describing the burden of pain to identifying the relational, clinical, and structural conditions that helped women feel safer, more supported, and more able to live with persistent pain.

Participants described a range of resources that made pain more manageable: validating support, practical assistance, effective pain relief, psychological care, access to information, individualised treatment, multidisciplinary services, and opportunities to reclaim agency. These forms of support did not remove the complexity of persistent pain, but they could change how participants lived with it. They reduced isolation, softened self-doubt, enabled participation, helped regulate distress, and restored some sense of choice in bodies and systems that often felt unpredictable.

This theme is organised into four subthemes: Support as validation, belonging, and survival; Pain relief as participation; Mental health care as pain care; and A suite of care: individualised, multidisciplinary, and agency-building.

Support as Validation, Belonging, and Survival

Support was one of the most important resources that helped participants live with persistent pain. However, participants' accounts suggest that not all support was equally helpful. Support was most meaningful when it believed pain without requiring proof, adapted to participants' changing capacity, and allowed them to speak honestly without being minimised, compared, or rushed toward solutions. In this sense, support helped counter some of the harms identified in earlier themes: disbelief, isolation, self-doubt, and the pressure to perform normality.

For some participants, support interrupted the fear that others would think they were exaggerating or faking pain. This fear could persist even in situations where pain was visibly severe or medically recognised. One participant described being supported by a colleague while receiving emergency care:

I was sitting there being like, 'I hope they don't think that I've faked this to get out of work', and then I was there with my colleague, who came down to support me.

She's lovely, and she was like, 'Babe, you're literally having IV morphine right now. I don't think you're faking this. You nearly fainted in front of everyone'. She was like, you need to give yourself a break.

This quote shows how deeply participants could internalise fears of not being believed. Even while receiving medical assistance for severe pain, the participant worried that others might think she had fabricated pain to avoid work. Her colleague's response provided external validation at a moment when the participant was doubting herself. Support therefore did not only offer practical help; it helped the participant recognise her own pain as legitimate and release, even briefly, the pressure to prove that she was really suffering.

Several participants emphasised the importance of support that did not require them to repeatedly justify their pain. This was especially important because earlier themes showed how often participants had to explain, defend, or make their pain credible. One participant insisted that “having a support system that doesn't question your pain and is open to going on the journey with you, no questions asked, is very important.” The phrase “no questions asked” is significant because participants' accounts across the findings have shown how often pain required explanation, proof, or defence. Support that did not question pain reduced this burden. It allowed participants to be believed without having to convincingly perform pain, educate others, or defend the seriousness of their symptoms. In this sense, support functioned as a form of validation: it gave participants space to experience pain without also having to justify it.

These accounts align with literature showing that social support is an important part of living with endometriosis-related pain and can shape quality of life, emotional wellbeing, and the ability to manage symptoms. Fang et al. (2024) emphasise the importance of social and emotional support from partners, family members, and support

groups in endometriosis and pelvic pain care. The present findings add qualitative depth by showing that support mattered not only because it provided practical help, but because it validated pain without requiring constant explanation. For participants whose pain had often been doubted or minimised, being believed by others could reduce the emotional labour of proving pain and make the experience less isolating.

Support was meaningful when it involved adaptation. Participants described friends, partners, family members, and colleagues who changed expectations, accommodated cancellations, or found different ways to remain connected. One participant described how her friends adapted social connection around her capacity:

I guess when you've got good people that can show a bit of grace, and my friends are really accommodating. Like my hangouts with my friends look like phone calls in the evening, or they might come to me or we might video chat. My friends take the barrier of pressure away, but always make a point of including me.

This account emphasises that support helped participants remain socially connected without exceeding their limits. The participant's friends did not simply express sympathy; they changed the conditions of participation. By reducing pressure while still including her, they helped protect her from the social isolation and guilt described in Theme 3. This kind of support recognised fluctuating capacity without treating it as withdrawal, unreliability, or lack of interest.

Participants valued support that allowed pain to be present without immediately trying to fix it. Although advice was often well-intentioned, participants described how

unsolicited suggestions could reinforce self-blame. One participant explained how advice could make pain feel like a personal failure:

The belief that it's my own fault also comes from the idea that people like to think they have the answers... like, 'Oh, you should just work out. Make sure you eat that. Have you tried yoga?' I think that also perpetuates the lie so that I'm like, oh, so if I did just work out 30 minutes every day a week, I would be better.

This reflection suggests how advice can become burdensome when it implies that pain persists because the person has not tried hard enough. Suggestions such as exercise, diet, or yoga may be helpful for some, but when offered without understanding, they can intensify guilt. Support was therefore most helpful when it acknowledged pain rather than turning pain into a problem the participant had failed to solve. The issue was not advice itself, but advice that shifted responsibility back onto the person in pain.

Another participant described the rarity and importance of people who could simply sit with suffering without offering solutions. This kind of support was valuable because it did not require pain to be made positive, manageable, or easy for others to witness. She described this as someone being willing to "sit in the muck":

It's very rare to find a person who will sit in the muck, in your muck, with you. And everyone else sees you ,and they see you like dirt of some kind... That's really scary for them, and all they're actually trying to do is comfort themselves. And so just ends up [that] you feel really terrible. As opposed to someone who can just look at you and be like, yep, I've got it too. Everyone has it. And just not being scared of that.

I'll sit with you and your dirt. And if you want help, I'll come help you. And if you never want help, that's OK too.

This quote captures the emotional quality of helpful support. The participant suggests that pain and chronic illness can be uncomfortable for others to witness, leading people to respond by trying to fix, minimise, or distance themselves from it. In contrast, support that “sits in the muck” does not require pain to become neat, positive, or resolved. It provides emotional safety by allowing suffering to exist without judgement. This kind of support was powerful because it reduced the loneliness of pain without demanding that the participant explain, improve, or reassure others.

Connection with others who had endometriosis could reduce isolation. Participants described feeling understood by people who shared similar experiences or knowledge of the condition. This shared understanding could make painful experiences easier to speak about because less explanation was required:

It's very especially meaningful when you're talking to someone who also has endo or who knows about it ... Someone who knows, it's so, so great. Like we're always both smiling, and we're laughing, and relating over these terrible things. Whereas when it's someone who has no idea, it's just like a pointless conversation.

This account highlights the relief of shared understanding. Speaking with someone who “knows” reduced the need for explanation and allowed participants to relate through experiences that might otherwise be difficult to communicate. Peer connection therefore provided belonging and validation that was not always available in wider social contexts.

Support did more than provide comfort; it reduced the isolation created by invisible and poorly understood pain.

This finding also shows how support could create belonging where pain had previously produced isolation. Existing research has noted that people with endometriosis may struggle to communicate pain or find others who understand the experience (de C Williams & McGrigor, 2024). Participants' accounts in the present study show why peer and community support could be so meaningful. Speaking with others who recognised the reality of endometriosis-related pain reduced the need to translate, justify, or minimise symptoms. In this way, support operated as more than emotional comfort; it provided a shared language through which participants could feel understood, less alone, and more legitimate in their own experiences.

However, peer spaces were not always supportive. Some participants described online groups as anxiety-provoking, competitive, or invalidating. Shared diagnosis did not automatically guarantee safety or understanding:

And instead of anyone answering my question, it turned into things like, 'Why would you be having five surgeries? Like that's so excessive.' Or you know, and it was kind of like for a community that's supposed to look after each other, it very much my endo is worse than your endo.

This experience complicates the idea that all peer support is helpful. While shared experience can reduce isolation, support spaces may also reproduce comparison, fear, or competition over whose pain is most legitimate. In this account, the participant entered a

community expecting care, but instead encountered judgement and comparison. For participants already carrying self-doubt, these interactions could increase anxiety or distress rather than reduce it. Support was therefore most helpful when it validated different experiences rather than requiring participants to prove the severity of their suffering.

Despite this complexity, participants consistently identified supportive environments as central to living with pain. Support mattered not only because it helped in moments of crisis, but because it shaped the broader conditions in which participants coped. One participant reflected on how her surrounding support shaped her ability to live with endometriosis:

And I'm very aware that I'm a product of my surroundings. And I think that's been a huge part of it. Good support, encouragement to do what I want to do, a loving partner, good friends, supportive mum, a good specialist, I've been really fortunate that all of those factors have been positive for me. Which is why I firmly believe that is why I can sit here and say this. Yes, I've put in the work, but sometimes you are a product of your environment.

This quote resists an overly individualised account of coping. The participant acknowledges her own effort, but also recognises that her capacity to live with pain was shaped by her environment: supportive relationships, encouragement, practical resources, and a good specialist. Pain became more liveable not simply because she was resilient, but because she was surrounded by conditions that supported resilience. This is

important because it shifts attention away from coping as an individual responsibility and toward the relational and structural conditions that make coping possible.

Together, these accounts show that support helped participants live with pain by providing validation, belonging, adaptation, and emotional safety. Helpful support did not require participants to prove pain, perform wellness, accept unsolicited advice, or turn suffering into something comfortable for others. Instead, it believed pain, made room for fluctuating capacity, and reduced the isolation of living with a poorly understood condition. Support therefore functioned as a protective resource, not because it removed pain, but because it changed whether pain had to be carried alone.

Pain Relief as Participation

Pain relief was central to making pain liveable. Participants' accounts show that medication and practical pain-management strategies were not merely symptom-control tools; they made participation in life possible. Effective pain management allowed participants to work, study, parent, sleep, leave the house, complete daily tasks, and reduce the psychological intensity of pain. Conversely, unmanaged pain reduced participation, increased isolation, worsened mental health, and could leave participants vulnerable to desperate or unsafe attempts to find relief.

One participant described the relationship between pain control, quality of life, and mental health. For her, keeping pain within a manageable range was necessary to prevent pain from becoming psychologically overwhelming:

And she knows that if I stop my quality of life, that's when the dark thoughts keep coming in and things like that. I have to maintain that pain level to a certain extent, or it just gets too overwhelming.

This extract recognises that pain relief was closely tied to mental health and participation. Maintaining pain at a manageable level helped the participant stay connected to life and reduced the risk of “dark thoughts.” Pain management therefore acted as a protective resource. It did not simply reduce physical sensation; it helped prevent pain from becoming psychologically overwhelming.

Participants described how finding effective medication could change their ability to function. The following account contrasts unmanaged pain, which affected eating and basic functioning, with pain that was currently more controlled:

The juggle, trying to figure it out. And I lost like 10 kilos when the pain was really bad because I just couldn't eat and this was before we put me on the slow release tramadol... It's managed at the moment. ... You can't function unless you've got something.

This quote captures the severity of unmanaged pain and the significance of relief. The participant's pain affected eating and basic functioning before medication helped make it manageable. The phrase “you can't function unless you've got something” highlights that medication was not experienced as optional or excessive; for some participants, it was the condition that made ordinary life possible. Pain relief therefore shaped not only symptom intensity, but access to everyday functioning.

For some, medication enabled roles and activities that would otherwise have been inaccessible. One participant described opioid medication as central to her ability to study, parent, and work:

I'm a grade A student, I still do all my things. I still, I can manage to study, sit and study. I can manage to do exams. I can manage to be a mum. I can manage to go to work, and it's just simply because of opioid medication.

This account is crucial because it reframes pain medication as participation. The participant's ability to study, sit exams, parent, and work depended on effective pain relief. For this participant, adequate pain relief enabled study, parenting, and work. This does not mean that opioid medication was simple, risk-free, or universally appropriate. Rather, the account shows that pain management should be understood in relation to functioning, safety, quality of life, and participation.

Participants developed practical systems to manage pain and reduce panic. These systems included medication routines, heat, ice, TENS machines, baths, stretching, and emergency kits. One participant described carrying a pain-management kit everywhere:

On a normal day, I carry like an emergency kit with me everywhere that has my TENS machine, and it has some deep heat in it. It has all of my pain medications like paracetamol, celecoxib, codeine and Sevredol if I really need it. And that comes with me everywhere, and a little power bank and a charging cable in case the TENS machine dies.

This extract reveals how pain management became part of everyday preparedness. The emergency kit provided practical tools, but it also offered psychological reassurance. Being prepared reduced the fear of being caught without options if pain escalated. In this sense, practical pain management helped participants regain some control over an unpredictable body.

These accounts align with literature showing that endometriosis-related symptoms affect work, study, social participation, relationships, and quality of life. However, the present findings extend this literature by showing that pain relief mattered because it enabled participation, not only because it reduced symptoms. Participants valued relief when it allowed them to attend work, study, parent, socialise, sleep, move, or simply regain a sense of being able to act. Pain relief therefore had psychosocial meaning: it restored access to everyday life. This suggests that care should not be evaluated only by whether pain disappears, but also by whether people regain capacity, agency, and participation.

Knowledge about medication also mattered. Some participants described learning that pain needed to be managed early rather than chased once it became severe. This changed how they responded to pain and helped reduce escalation:

The biggest thing I've learnt about pain management is to preempt [it]. Someone said it to me, some doctor said, that you can't chase pain or it's really hard to chase pain. And so what they mean by that is if you're in acute pain and then try and start medicating. And I would often do that in the past as well. I would wait until things

were so bad, but actually now I start taking pain medication before I have any sign of being in pain and build it up.

This quote shows how information could change participants' relationship with pain. Learning to pre-empt pain helped the participant avoid escalation and reduced the sense of being overtaken by pain. Pain management was therefore not only about access to medication, but also about knowledge, timing, and confidence in using available tools. This suggests that education about pain management can support agency, particularly when participants are trying to manage unpredictable symptoms.

At the same time, participants were aware of the risks and limits of medication. Some worried about long-term opioid use, side effects, or becoming dependent on medications that were necessary for functioning. Others described being offered medications that made them feel sedated, unsafe, or unable to work. The importance of pain relief therefore sits alongside the need for careful, individualised support. When pain relief was inadequate, stigmatised, or poorly monitored, participants were left to manage the consequences alone.

This finding is important because endometriosis-related pain is not always fully resolved by diagnosis, hormonal treatment, surgery, or lesion-focused care. As-Sanie et al. (2025) note that pain can persist or recur and that endometriosis-related pain may involve nociceptive, neuropathic, and nociplastic mechanisms. Participants' accounts gave lived meaning to this clinical complexity. Relief was often partial, temporary, or dependent on combining strategies, yet even imperfect relief could be meaningful when it allowed

participants to participate in life. This complicates a cure-focused understanding of care by showing that symptom reduction, functional capacity, and liveability were closely connected.

Overall, pain relief made pain manageable by allowing participants to participate in ordinary life. It reduced pain intensity, helped prevent psychological overwhelm, and fostered a sense of preparedness. However, participants' accounts also show the need for pain management to be taken seriously, discussed openly, and tailored to individual bodies and risks. Without adequate pain relief, persistent pain could reduce participation, worsen mental health, and push participants toward increasingly desperate attempts to cope.

Mental Health Care as Pain Care

Importantly, participants valued psychological care when it validated pain as real and embodied, rather than using psychological explanations to dismiss pain. This distinction matters because earlier experiences of psychologisation often made participants feel that pain was being treated as imagined or exaggerated. In contrast, helpful mental health care acknowledged the reality of pain while providing tools to manage the distress, fear, guilt, and nervous-system responses that pain produced.

Despite this need, several participants reported that psychological support was not routinely offered. This absence was significant because participants often described endometriosis-related pain as emotionally distressing, traumatic, and difficult to carry alone. One participant reflected that “all throughout my years, someone, a doctor, has

never said, 'Would you like to talk to someone about what you're experiencing?' Because it is quite traumatic, and not once did, not anyone mention it?"

This extract highlights a gap in care. The participant identifies endometriosis-related pain as traumatic, yet describes never being asked whether she wanted to speak to someone about it. This suggests that the emotional consequences of persistent pain were often left unaddressed until participants sought support themselves or reached crisis points.

For participants who did access counselling or psychological care, it could provide a space to externalise thoughts and reorganise emotional distress. This was important because pain-related distress often became internalised, repetitive, and difficult to process alone. One participant described counselling as "That's really lovely to just go there... Dump everything in my brain and then I get to rearrange them, put them in the right places, throw out what isn't useful, and then like, pop it back in."

This quote captures counselling as a form of emotional processing. It gave the participant a space to place thoughts outside herself, organise them, and decide what was useful to carry forward. This mattered because pain-related distress often became internalised, repetitive, and isolating.

Psychological support helped participants feel that their pain was real and reduced the mental labour of questioning themselves. This links back to earlier themes, where participants often had to prove pain to others and then began doubting themselves. Another participant described, "It's helped me. It's just really helped it feel real. ... And so I

put less of that kind of mental gymnastics or anxiety into like worrying about whether it's real and can just accept that it's real.”

This account links psychological care directly to the legitimacy of pain. The participant did not need therapy because the pain was imaginary; rather, psychological support helped undo the self-doubt produced by years of invalidation. It reduced the “mental gymnastics” involved in repeatedly questioning whether pain was real enough to justify care, rest, or support.

These accounts align with Dowding et al. (2024), who found that women sought psychological therapy for support with trauma, grief, anxiety, depression, uncertainty, loss of identity and ability, and adjustment to chronic illness. Participants in the present study similarly described psychological support as helping them live with the consequences of persistent pain. Importantly, this did not mean that pain was treated as imaginary or purely psychological. Rather, mental health care became pain care because it supported participants to manage distress, fear, self-doubt, grief, and the emotional labour of living with a chronic and uncertain condition. Psychological support therefore addressed the psychosocial burden of pain, not the legitimacy of pain itself.

Pain psychology was especially valuable for some participants because it helped them understand their own pain patterns. This kind of care was useful when it moved beyond generic reassurance and offered an individualised explanation of how pain, stress, fear, and coping interacted. One participant described pain psychology as central to regaining control:

So the pain psychologist that I saw was extremely helpful. She was probably one of the biggest things to help me take control back of my life, and that was really just working with someone who could explain it and who gets to know you so they can explain how you seem to experience pain.

This reflection reveals that mental health care could restore agency through understanding. The pain psychologist did not simply provide generic reassurance; they helped the participant understand how she personally experienced pain. This individualised explanation allowed her to make sense of her responses and develop strategies for living with pain.

Participants described psychological care as helping them break cycles between stress and pain, reduce guilt around rest, manage agitation, apologise and repair relationships, use grounding techniques, and remain present during medical encounters. These skills mattered because pain affected not only the body but also attention, mood, relationships, and self-perception. Psychological care helped participants build a buffer beyond simply enduring pain.

This finding is consistent with literature suggesting that psychological support may improve aspects of quality of life, emotional wellbeing, control, coping, and adjustment in endometriosis-related pain, even when pain intensity itself is not fully resolved (del Pino-Sedeño et al., 2024; Dowding et al., 2024). Hansen et al. (2023), for example, found that psychological intervention did not significantly reduce pelvic pain intensity but improved domains such as control and powerlessness, emotional wellbeing, and social support.

Participants' accounts in the present study help explain why these outcomes matter.

Psychological care was valuable because it helped participants feel less powerless, make sense of pain, regulate distress, and rebuild a more compassionate relationship with themselves. This reinforces the idea that meaningful pain care includes liveability, not only pain reduction.

One participant described the lack of emotional support through the metaphor of being on fire. This metaphor is important because it shows that emotional support was experienced as urgent, not optional. She described feeling observed rather than helped:

I just couldn't believe how lacking the emotional support side of things was. It's almost like you're on fire and people are just sort of sitting there taking notes. And it's like, 'I'm on fire right now, do you want to give me a fire blanket or like something?'

This quote illustrates the urgency of emotional support. The participant did not experience psychological care as an optional addition to medical treatment; she needed help while suffering was happening. The metaphor of a "fire blanket" suggests containment, safety, and immediate relief from overwhelm, rather than observation without response. Without this support, participants could feel watched, assessed, or documented, but not meaningfully helped.

Mental health care therefore mattered because persistent pain was emotionally and physiologically demanding. Psychological support did not mean that pain was "all in the head," nor did it necessarily change disease progression. Instead, it helped

participants manage the distress that pain produced, understand pain–stress cycles, reduce self-blame, and live with pain in ways that felt less overwhelming. In this sense, mental health care was pain care.

A Suite of Care: Individualised, Multidisciplinary, and Agency-Building

Participants' accounts suggest that making pain liveable required care that was individualised, multidisciplinary, and agency-building. Participants did not describe one universal treatment that worked for everyone. Instead, they emphasised that bodies responded differently, side effects mattered, goals varied, and people needed different combinations of medical, psychological, physical, and lifestyle support. The strongest accounts of helpful care were those in which participants felt listened to, informed, and involved in decisions about their own bodies.

A recurring concern was that care could feel too standardised. Participants described being offered similar pathways, such as hormones, painkillers, surgery, or “first-line” treatments, even when these had not worked or had caused unacceptable side effects. One participant described the need for care that could meet people as individuals:

The medical system is very interesting and that it is a bunch of checklists, but I would argue that the best way to help someone is to, like, meet them where they're at and everybody's different and should be treated like everything's individual. And if you try to put everything in a box, so many people will not fit and will not get like the help that they need.

This extract emphasises the importance of individualised care. The participant does not reject medical structure altogether, but argues that checklist-style care can miss people whose bodies or needs do not fit standard pathways. For participants with persistent pain, being treated as an individual mattered because ineffective treatments could prolong suffering, increase side effects, and intensify feelings of invalidation. Individualised care therefore meant more than choice or preference; it meant recognising that standard pathways did not always match lived complexity.

Participants described the emotional impact of treatments being assumed to work because they helped others. This could be especially difficult when side effects were severe or when treatments worsened symptoms rather than improving them. One participant reflected on the need for closer monitoring and greater recognition of variation:

I guess I would want more emphasis on ... one thing might help some patients and make things so much worse for others. I think that needs to be accepted and monitored more closely because for me, I was taking whatever medication that the doctors gave me and it actually made things so much worse for me in all areas of life.

This sentiment underscores that individualised care is not only about preference; it is about safety and quality of life. Treatments that help some people can worsen pain, mood, functioning, or daily life for others. When participants were told that a treatment “should” work, failure of the treatment could be experienced as personal failure.

Individualised care could reduce this burden by recognising variation as expected rather than exceptional.

The lack of individualised care could also affect validation and agency. Participants wanted clinicians to share information, explain options, and recognise that patients were trying to understand their own bodies. One participant described how not having her needs addressed made care feel disempowering:

I think not having ... my individual needs kind of addressed really led to me not feeling validated, and I think ... it's a tricky space in that the doctors almost hold the information and the power, I guess. And so it's like this is my body and I'm trying to get help with it. And you're not really sharing what can help me is what it feels like. And I think that's what made me feel the most invalidated.

This quote links individualised care to power. The participant was not only seeking treatment; she was seeking information about her own body. When information was held by clinicians and not shared in a way that supported decision-making, care felt disempowering. This illustrates how agency depends on access to knowledge, not simply access to appointments.

Participants wanted care that recognised pain as multidimensional. Several described the value of combining medical treatment with psychological care, pelvic physiotherapy, movement, diet, sleep support, and other strategies. One participant described that a whole-systems approach “is just so important because ... we're

multidimensional people, we should have a multidimensional flow approach for saying that is affecting you systemically in different aspect areas of your body.”

This extract brings together the logic of Theme 5. Persistent pain affected participants physically, psychologically, socially, and practically; therefore, care also needed to be multidimensional. A whole-person approach acknowledged that pain was not only located in one body part or solved by one intervention. It also recognised that improving life with pain required attention to the different systems, relationships, and supports that shaped participants’ wellbeing.

Multidisciplinary care was especially meaningful when it helped participants understand and treat different contributors to pain. This could move care beyond a single disease label without dismissing endometriosis itself. One participant described the value of shifting attention to the pelvic floor:

That's the difference. When we're treating the symptoms for what they are versus the endo as a whole, you can get different results. So when we changed focus to ... we're not saying you don't have endo. We're just going to pop that here for now, but let's look at the pelvic floor for what it is. What can we do to help with the pelvic floor? Because that is already causing problems.

This quote demonstrates how multidisciplinary care could make pain more manageable by identifying treatable contributors. The participant’s pain was not dismissed as unrelated to endometriosis; rather, care became more specific by recognising that pelvic floor tension could require its own treatment. This kind of care helped participants

move beyond a single disease label toward a more practical understanding of what might reduce pain. It also shows how validation and expansion can coexist: clinicians could affirm endometriosis while also exploring other sources of pain and support.

Participants valued having multiple tools rather than being offered only surgery, hormones, or medication. A “suite” of care was important because it could provide structure while still allowing for different needs, goals, and limits. The same participant described the kind of resource she wished had been available:

I think if I could have my pick, it would be a suite, because not everyone wants surgery. Not everyone wants to take pharmaceutical drugs. Not everyone wants to give up work. I think if there was a resource that was designed that said, if you wanted a non-surgical option, ask for a referral to the pain clinic. If you wanted a drug option, these are the ways you can start. If you wanted to talk surgical options, this is what a standard lap [laparoscopy] looks like. This is your recovery time. I think a suite in terms of what the basic starting points are of treatment options.

This account captures that a suite of care would provide structure without forcing a single pathway. Participants wanted to know what options existed, what each involved, and how different choices might fit their goals and limits. This kind of information could reduce the feeling of “running blind” and allow participants to make decisions with greater confidence. A suite of care therefore offered not only treatment options, but a way to make care more transparent and navigable.

For one participant, the value of whole-person care lay not in the promise of cure, but in reducing fear and increasing psychological safety:

And so I think, yeah, having less fear and more safety, and that psychological safety, and people who at least have had some training around what it's like, even if they haven't experienced it, would go a long way to making it a more solvable thing, I think. But I don't know if that would have changed my trajectory in terms of my disease, but I do think it would just make me feel a lot better. That's important to me.

This quote captures the central meaning of liveability in this theme. The participant did not suggest that psychologically safe, informed care would necessarily change the biological course of the disease. Instead, she identified that care could change how the disease was lived. Less fear, greater safety, and contact with people who understood endometriosis-related pain could make the condition feel more manageable, less isolating, and less overwhelming. This distinction is important because it shows that meaningful care cannot be measured only by cure, lesion removal, or symptom elimination. For participants, care also mattered when it reduced fear, supported agency, and made persistent pain feel more possible to live with.

This finding aligns with literature emphasising validation, psychological support, reliable information, and coordinated multidisciplinary care in endometriosis. Aerts et al. (2018) argue that endometriosis care should address physical, mental, sexual, and social dimensions, while Fang et al. (2024) emphasise the need for long-term, comprehensive,

coordinated, and patient-centred care for endometriosis and pelvic pain. Dowding et al. (2024) similarly show that psychological care can support adjustment, coping, and the emotional consequences of living with endometriosis. The COMPASS model also highlights agency, sense-making, validation, health literacy, access to care, and multidisciplinary management in endometriosis-related persistent pain (Pickup et al., 2025). The ASPIRE consensus provides a useful visual example of this direction in Figure 1 by positioning the person with endometriosis at the centre of a network of expertise, including specialist gynaecology, surgery, pain management, physiotherapy, psychology, fertility care, primary care, peer support, and allied health expertise (Amnatbuddee et al., 2025). Participants' accounts illustrate why this kind of model matters: their needs were not confined to diagnosis or surgery, but included pain relief, validation, mental health support, information, communication, continuity, psychological safety, and agency.

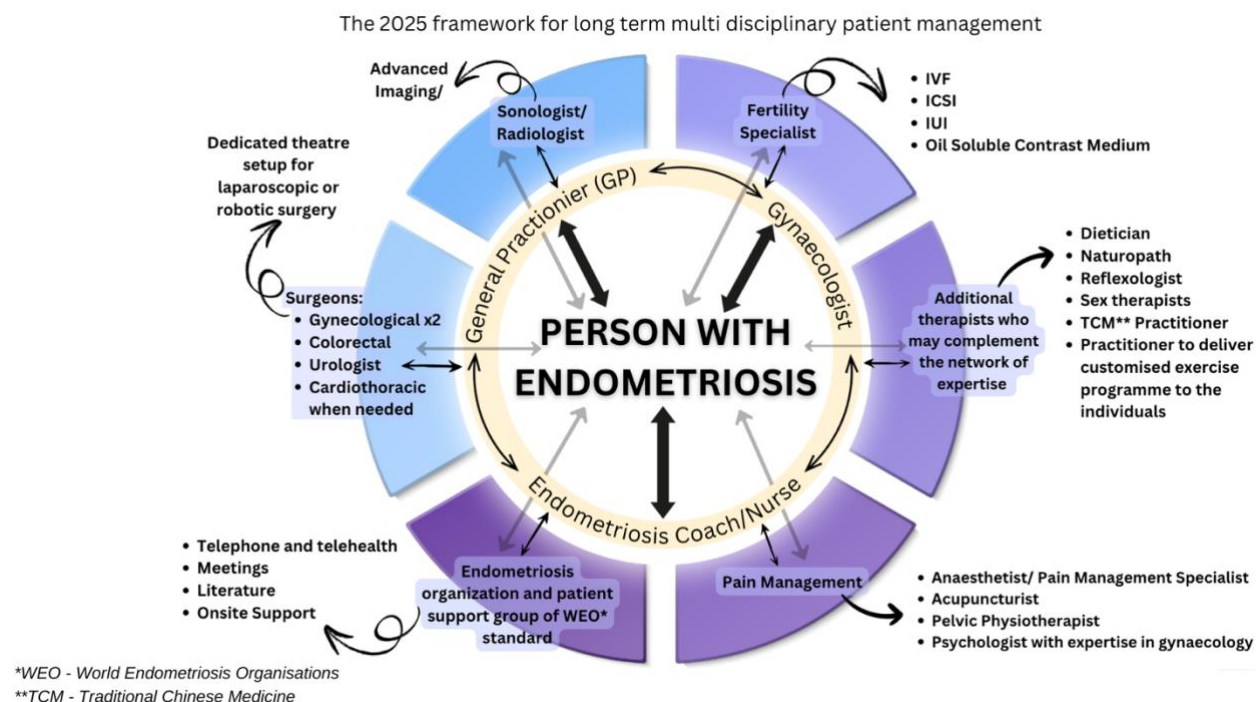
The same participant connected choice directly to power. For people living with persistent pain, having options could matter because so much of pain already felt outside their control. She explained that, "If everything was offered as a suite, like I said, it gives you a bit of power back, and a bit of control. ... I think it's the education piece around it's not just surgery and birth control."

This quote is central to the theme because it shows that agency was not simply about advocating harder. Agency came from having information, options, and permission to choose what was acceptable. For people living with chronic pain, where so much felt outside their control, choice itself could be therapeutic. The participant's emphasis on

education also shows that agency depends on knowing what is available, rather than being expected to request options that have never been clearly explained.

Figure 1

ASPIRE Framework for Long-Term Multidisciplinary Patient Management in Endometriosis



Note. This diagram outlines the multidisciplinary care network recommended for endometriosis management. Reproduced from “ASPIRE Consensus on the Structure of Care in Endometriosis: Networks of Expertise,” by S. Amnatbuddee et al., 2025, *Fertility & Reproduction*, 7(2), p. 86. Copyright 2025 by World Scientific Publishing Company. Reproduced under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International licence.

Agency was built through knowledge and advocacy. Participants described learning how to speak up, ask questions, challenge recommendations, request tests, and make decisions based on what they knew about their own bodies. One participant described both the importance and difficulty of this process:

Being able to address it to what you know works for you. And just like, that's something I've had to teach myself. I'm the one who knows that. So I either say when I'm not comfortable with something, or I need to say what I want to do 'cause they just, they don't know that. And so you have to advocate for yourself, which is also terrifying.

This extract reveals the ambivalence of self-advocacy. Knowing one's body and speaking up could restore control, but it was also frightening. Participants should not have had to carry this responsibility alone. However, when supported by good information and collaborative care, advocacy helped participants become more active in shaping their pain management. The quote therefore frames agency as relational: it depended not only on the participant's confidence, but on whether care systems allowed her knowledge to matter.

Some participants described reaching a point where they felt more confident challenging dismissive or inappropriate responses. This confidence was often hard-won, emerging after years of normalisation, delay, or being told that pain was ordinary. Another participant offered advice to others beginning an endometriosis journey:

If I could advise anybody who's starting off on the endometriosis journey, be that squeaky wheel. Be that squeaky wheel. Annoy the crap out of your medical staff. Be

the one. Be the loudest one in the room. Don't let them stand over you and tell you that it's normal. 'Cause there's no way in hell that what we go through day in and day out, it's not normal. But definitely be that squeaky wheel advocate for yourself.

This account echoes Theme 1 but moves it toward agency. The participant's advice is grounded in the recognition that pain should not be normalised. However, it also reveals a burden: participants often had to become loud, persistent, and difficult to ignore in order to receive care. Agency was therefore both empowering and exhausting. While self-advocacy could help participants resist dismissal, the need to become the “squeaky wheel” also shows that responsibility for recognition too often fell on those already living with pain.

This finding also returns to the agency dimension of the COMPASS model (Pickup et al., 2025). Participants' accounts showed that good care was not only care that acted on the body, but care that helped them understand options, make decisions, and feel involved in what happened next. This adds nuance to discussions of multidisciplinary care by showing that coordination alone is not enough. Care also needed to be validating, communicative, flexible, and agency-building. Without these qualities, even technically appropriate care could leave participants feeling unsupported or uncertain.

The most helpful care appeared to be care that did not leave participants to carry this burden alone. Individualised and multidisciplinary care helped participants understand their pain, access different forms of support, and make informed decisions. A

suite of care offered more than treatment options; it offered participants a way to regain control in the context of chronic pain.

Overall, this theme shows that participants made pain more liveable through validation, support, relief, mental health care, and individualised whole-person approaches. The findings align with existing literature emphasising social support, psychological care, multidisciplinary management, validation, agency, and patient-centred endometriosis care. However, they extend this literature by showing what these forms of care meant in participants' everyday lives. Support mattered because it reduced isolation and the need to keep proving pain. Pain relief mattered because it enabled participation, not only because it reduced symptoms. Mental health care mattered because it helped participants carry the emotional, relational, and identity-related consequences of persistent pain without implying that pain was psychological in origin. Multidisciplinary care mattered because no single intervention addressed the full experience of persistent pain. Together, these findings suggest that making pain liveable requires more than treatment of disease alone. It requires care that recognises pain as embodied, psychosocial, socially situated, and shaped by access to validation, relief, agency, and coordinated support. This final theme completes the analytic movement of the chapter: from pain being questioned, to pain being prolonged, socially managed, internally carried, and finally made more liveable.

Synthesis of the Five Themes

Taken together, the five themes show that endometriosis-related persistent pain was not experienced as a symptom isolated within the body. Rather, pain became psychosocial through the ways it was recognised, delayed, socially managed, internally carried, and made more liveable. Across participants' accounts, pain moved through an analytic pattern: it was first questioned, then prolonged through care pathways, socially managed in everyday life, internally carried through distress and self-doubt, and finally made more liveable through support, relief, and whole-person care.

The first theme showed that pain legitimacy was not automatic. Participants had to learn that their pain was abnormal, convince others that it was real, and continue defending pain when it did not appear in expected ways. This established legitimacy as an ongoing psychosocial process rather than a single moment of recognition or diagnosis. The second theme showed that healthcare pathways shaped how long participants remained in pain and how much uncertainty they carried. Waiting, cost, fragmented care, and uneven access did not merely delay treatment; they shaped agency, trust, emotional burden, and the experience of living in suspended time.

The third theme showed how persistent pain had to be managed socially. Because pain was unpredictable and often invisible, participants had to plan around uncertainty, make decisions about disclosure, perform normality, and reorganise work, study, relationships, intimacy, and social life around fluctuating capacity. The fourth theme turned inward, showing how pain was carried through grief, guilt, self-doubt, rumination,

psychological distress, identity disruption, and efforts to rebuild self-compassion and acceptance. These internal experiences were not separate from the earlier themes. They were shaped by the cumulative effects of dismissal, waiting, uncertainty, invisibility, and disrupted participation.

The final theme showed that pain could be made more liveable through validation, social support, pain relief, psychological care, and individualised whole-person approaches. Participants did not describe liveability as cure, resignation, or simple coping. Rather, liveability referred to the conditions that made life with persistent pain feel safer, more supported, more manageable, and more possible. This included being believed, having access to relief, receiving psychologically safe care, maintaining participation, and feeling some agency in treatment and daily life.

Overall, the findings suggest that endometriosis-related persistent pain cannot be understood through diagnosis, disease visibility, or treatment history alone. Persistent pain was shaped by interactions between bodily symptoms, emotional distress, cognitive meaning-making, interpersonal relationships, social expectations, and healthcare systems. The central contribution of this chapter is therefore to show how endometriosis-related persistent pain becomes a whole-person experience: pain is felt in the body, but it is also shaped by whether it is believed, how long it is left untreated, how it is managed socially, how it is carried internally, and what forms of care make it more liveable.

Chapter Five: Conclusion

Chapter Overview

This chapter concludes the thesis by synthesising the key findings, contributions, implications, strengths, and limitations of the study. The research explored the psychosocial factors, dynamics, and processes that shape the lived experience of endometriosis-related persistent pain among women in Aotearoa New Zealand. Drawing together the literature, methodology, findings, and discussion, this chapter reflects on what the study contributes to understandings of persistent pain as an embodied, emotional, social, and healthcare-mediated experience.

Chapter Four integrated the presentation of participants' accounts with relevant literature by considering how the findings aligned with, extended, and complicated existing research across each theme. This chapter does not repeat that theme-by-theme discussion. Instead, it synthesises the study's overall contribution, implications, strengths, limitations, and directions for future research.

Summary of the Study

This study aimed to explore the psychosocial factors, dynamics, and processes that shape the lived experience of endometriosis-related persistent pain. In particular, it examined how emotional distress, cognitive and meaning-making processes, interpersonal relationships, social recognition, support, and healthcare experiences influenced how pain was understood, managed, and lived with.

A qualitative design was used to centre participants' lived experiences and meanings. The study was informed by a biopsychosocial understanding of persistent pain and sensitised by feminist health perspectives on gendered pain, legitimacy, and healthcare dismissal. Thirteen women in Aotearoa New Zealand with clinically diagnosed endometriosis and endometriosis-related persistent pain took part in in-depth semi-structured interviews. Data were analysed using reflexive thematic analysis, which supported the development of patterns of meaning across participants' accounts while recognising the active role of the researcher in interpretation.

The analysis generated five themes: "No amount of pain should be normal": struggling to legitimise pain; Waiting in pain: care pathways, uncertainty, and the cost of access; Living with an unpredictable and invisible body; Carrying pain internally: distress, self-doubt, and self-compassion; and Making pain liveable: support, relief, and whole-person care. Together, these themes showed that endometriosis-related persistent pain was not only endured in the body, but also negotiated through healthcare systems, relationships, social expectations, internal meaning-making, and access to support.

Summary of Key Findings

The findings showed that endometriosis-related persistent pain was experienced as an embodied, psychosocial, and healthcare-mediated condition. Across participants' accounts, pain was not only something felt in the body; it was something that had to be recognised, explained, managed, hidden, endured, interpreted, and made liveable. The five themes developed in this study can be understood as an analytic movement: pain

questioned, pain prolonged, pain socially managed, pain internally carried, and pain made more liveable.

The first theme, “No amount of pain should be normal”: struggling to legitimise pain, showed how participants struggled to have pain recognised as real, abnormal, and worthy of care. Participants described severe menstrual and pelvic pain being normalised, minimised, or psychologised. Pain was particularly difficult to legitimise when it did not appear clearly on scans, when participants looked composed, or when their distress was interpreted as anxiety or overreaction. Diagnosis often provided validation because it gave participants evidence that their pain had a recognised basis. However, legitimacy remained fragile when pain persisted after diagnosis or treatment. This theme showed that participants were not only managing pain; they were also managing the burden of proving that pain was real.

The second theme, Waiting in pain: care pathways, uncertainty, and the cost of access, showed how healthcare pathways shaped the duration and emotional burden of pain. Waiting was not experienced as passive time before treatment, but as time spent living with pain, uncertainty, functional limitation, financial pressure, and fear about the future. Access to private care, insurance, family support, health literacy, and flexible work arrangements could increase agency or reduce waiting, but these resources did not necessarily remove pain. Fragmented care also created emotional and administrative labour, as participants had to chase appointments, repeat histories, process complex information, and coordinate continuity across services. This theme showed that

healthcare systems did not simply respond to pain; they actively shaped how pain was lived.

The third theme, Living with an unpredictable and invisible body, showed how persistent pain affected participants' everyday social worlds. Pain could appear suddenly, disrupt plans, and make work, study, social life, and relationships difficult to sustain. Because pain was often invisible, participants had to manage disclosure, explain recurring symptoms, mask distress, and perform normality. Appearing well could protect participants socially, but it could also make their suffering harder for others to recognise. This theme showed that persistent pain created social labour as well as physical limitation, as participants tried to remain reliable, capable, and understandable while living with a body that could not always be predicted or seen.

The fourth theme, Carrying pain internally: distress, self-doubt, and self-compassion, turned attention to the internal psychological burden of persistent pain. Participants described grief, guilt, self-doubt, rumination, distress, disrupted identity, and fear about the future. Repeated dismissal and uncertainty could make participants question their own perceptions, while ongoing pain could affect mood, self-worth, and the ability to imagine a stable future. At the same time, some participants described processes of acceptance, self-compassion, and identity reconstruction. This theme showed that the psychological impact of pain was not separate from physical pain or healthcare experience; it was shaped by the ongoing work of living with pain that was uncertain, disruptive, and often poorly recognised.

The fifth theme, Making pain liveable: support, relief, and whole-person care, showed what helped reduce the psychosocial burden of persistent pain. Participants valued support that validated their pain, relationships that allowed them to be honest, pain relief that enabled participation, psychological care that recognised pain as real, and multidisciplinary approaches that addressed more than lesions or symptoms alone. Importantly, making pain liveable did not necessarily mean making pain disappear. Rather, it involved creating conditions in which participants could feel believed, supported, informed, and more able to participate in life. This theme showed the importance of whole-person care that attends to pain relief, emotional wellbeing, social support, agency, and ongoing management.

Taken together, the findings show that endometriosis-related persistent pain was not reducible to symptom severity, diagnosis, or treatment history. Pain was shaped by whether it was recognised as legitimate, how long participants waited for care, how others interpreted invisible symptoms, how participants carried pain internally, and what forms of support made life more manageable. The study therefore supports a biopsychosocial understanding of persistent pain while also showing how gendered assumptions, healthcare structures, social expectations, and personal meaning-making shape the lived experience of endometriosis-related pain.

Contribution of the Study

This study contributes to understandings of endometriosis by foregrounding persistent pain as a psychosocial experience rather than only a clinical symptom. While

existing research has documented diagnostic delay, reduced quality of life, healthcare dismissal, and the emotional burden of endometriosis, this study brings these dimensions together by examining how pain was lived, interpreted, socially negotiated, internally carried, and made more liveable. The findings show that endometriosis-related persistent pain was shaped not only by bodily symptoms, but also by legitimacy, care pathways, social visibility, self-understanding, and support.

A key contribution of this study is its focus on persistent pain. Participants' accounts showed that diagnosis, surgery, or treatment did not always bring an end to pain or to the psychosocial consequences of living with pain. For some participants, diagnosis provided validation but did not resolve ongoing symptoms, uncertainty, distress, or the need to keep advocating for care. This focus helps move understandings of endometriosis beyond a diagnostic or lesion-focused framing and toward a whole-person understanding of pain as ongoing, relational, and contextually shaped.

The study further contributes to the Aotearoa New Zealand context by providing qualitative insight into how women with endometriosis-related persistent pain experienced healthcare pathways, public and private access, waiting, fragmented care, and support. Participants' accounts showed that access to care was not only a matter of treatment availability, but also of agency, affordability, health literacy, communication, and continuity. This is important because persistent pain was not lived outside the healthcare system; it was shaped by the pace, structure, and responsiveness of care.

Additionally, the findings contribute to psychosocial understandings of invisible and gendered pain. Participants described having to prove pain, explain pain, hide pain, and manage how pain was interpreted by others. This shows that pain legitimacy was not only a clinical issue, but a social and emotional one. The study therefore highlights the need to understand endometriosis-related persistent pain in relation to gendered expectations, social recognition, stigma, disclosure, and the pressure to remain functional despite ongoing symptoms.

Methodologically, the study contributes a reflexive qualitative account grounded in in-depth interviews with women living with endometriosis-related persistent pain. The use of reflexive thematic analysis allowed the research to move beyond listing impacts of pain and instead develop themes that captured patterns of meaning across participants' accounts. My insider position also shaped the research, supporting sensitivity and rapport while requiring ongoing reflexive attention to difference, assumption, and interpretation. This reflexive approach helped produce an analysis that attended to both shared patterns and variation within participants' experiences.

Overall, the study contributes a nuanced account of endometriosis-related persistent pain as real, embodied, socially situated, psychologically significant, and shaped by healthcare systems. It shows that making pain more liveable requires more than diagnosis or treatment alone. It requires recognition, validation, coordinated care, psychosocial support, and attention to the conditions that shape how pain is understood and endured.

Implications

These implications follow from the analytic movement of the findings: if pain was questioned, prolonged, socially managed, internally carried, and made more liveable through support, then care must address legitimacy, timeliness, social participation, psychological burden, and whole-person support. The findings have several implications for endometriosis care, persistent pain support, healthcare communication, education, and psychosocial practice. Overall, the study suggests that improving care for endometriosis-related persistent pain requires more than earlier diagnosis or lesion-focused treatment alone. While diagnosis and medical treatment remain important, participants' accounts showed that persistent pain also requires recognition, validation, coordinated care, emotional support, and attention to the social conditions that shape how pain is lived.

First, the findings highlight the importance of recognising pain as legitimate, even when it is invisible, difficult to measure, or not fully explained by scans or test results. Participants often described pain being normalised, dismissed, psychologised, or made difficult to prove. This suggests a need for healthcare encounters that begin from a position of validation and curiosity rather than suspicion or minimisation. Clinicians do not need to have immediate answers in order to acknowledge that a patient's pain is real and consequential. Validation may be particularly important for people who have experienced repeated dismissal, as disbelief can shape self-trust, help-seeking, and emotional wellbeing long after a consultation has ended.

Second, the findings suggest that menstrual and endometriosis education remains important. Several participants described growing up without clear language for recognising severe menstrual pain as abnormal. Greater awareness in schools, families, communities, and primary care may help people identify symptoms earlier and seek support sooner. Education should not only describe endometriosis as a condition, but also challenge the normalisation of severe menstrual pain and provide practical guidance about when pain warrants further investigation.

Third, the findings highlight the importance of timely and coordinated care pathways. Waiting was not experienced as neutral or passive; it was time spent living with pain, uncertainty, functional limitation, and fear about the future. Fragmented care also placed administrative and emotional labour on participants, who often had to chase appointments, repeat histories, and coordinate information across services. This suggests a need for clearer referral pathways, better follow-up systems, improved communication between services, and more support for patients navigating care. Continuity of care may be especially important for people with complex pain histories, recurrent symptoms, or pain that persists after treatment.

Fourth, the findings support the need for multidisciplinary and whole-person care. Participants did not describe one universal treatment or support pathway that worked for everyone. Instead, they valued different combinations of gynaecological care, pain relief, pelvic physiotherapy, psychological support, counselling, information, lifestyle strategies, social support, and specialist input. This suggests that endometriosis-related persistent pain should be approached as a multidimensional experience requiring flexible and

individualised care. Psychological support should not be framed as implying that pain is “in the mind.” Rather, counselling, pain psychology, grounding strategies, self-compassion, and acceptance-based approaches may help people manage the emotional and social consequences of pain while recognising that the pain itself is real and embodied.

Fifth, the findings have implications for workplaces, education providers, and social support systems. Participants described pain as unpredictable, invisible, and difficult to plan around. This affected their ability to work, study, attend social events, maintain relationships, and participate consistently in everyday life. Supportive workplaces and educational environments should recognise that fluctuating capacity does not mean unreliability or lack of commitment. Flexible arrangements, understanding around appointments or flares, and non-stigmatising communication may help reduce the additional social burden created by invisible pain.

Finally, the findings suggest that support should extend beyond symptom management to include agency and liveability. Participants valued care and relationships that helped them feel believed, informed, supported, and able to make decisions about their lives. Making pain liveable did not mean accepting inadequate care or giving up hope for relief. Rather, it meant creating conditions in which people could participate in life as fully as possible while living with uncertainty, symptoms, and changing needs. Endometriosis care should therefore attend not only to reducing pain, but also to supporting dignity, self-trust, participation, and quality of life.

Strengths and Limitations

This study has several strengths. First, the use of in-depth semi-structured interviews enabled participants to provide detailed accounts of endometriosis-related persistent pain in their own words. This was important because the study aimed to explore not only what participants experienced, but how they interpreted, managed, and made sense of pain within everyday, social, emotional, and healthcare contexts. The richness of the interview data supported a nuanced analysis of persistent pain as an embodied and psychosocial experience.

A second strength was the focus on persistent pain rather than endometriosis diagnosis alone. This allowed the study to examine pain that continued to shape participants' lives after diagnosis, treatment, surgery, or ongoing symptom management. This focus helped illuminate how pain legitimacy, healthcare pathways, social invisibility, internal distress, and support remained important even when participants had already received a diagnosis or accessed treatment.

A third strength was the reflexive qualitative approach. Reflexive thematic analysis supported the development of themes that captured patterns of meaning across the dataset rather than simply listing topics or experiences. My insider position also supported sensitivity to the topic and may have contributed to rapport during interviews. At the same time, this positioning required ongoing reflexive attention to assumptions, emotional responses, and the risk of over-identification. Supervision, memo-writing, repeated

engagement with transcripts, and attention to variation across participants' accounts helped support a careful and transparent analytic process.

The study also contributes locally by focusing on women in Aotearoa New Zealand. Participants' accounts provided insight into care pathways, public and private healthcare access, waiting, fragmented communication, and the social and emotional burden of living with endometriosis-related persistent pain in this context. Although the study does not claim to represent all people with endometriosis in Aotearoa New Zealand, it offers rich qualitative insight into experiences that are important for understanding persistent pain, healthcare access, and psychosocial support.

There are also limitations. The sample consisted of 13 participants, all of whom identified as women and were able to participate in English. The study therefore does not capture the experiences of people with endometriosis across diverse gender identities or those who may have wished to participate in other languages. The sample also included a relatively small number of Māori, Pasifika, Asian, migrant, rural, and financially constrained participants. Although participants varied in employment status, educational background, ethnicity, diagnosis history, and access to care, the study should not be understood as representative of all people with endometriosis in Aotearoa New Zealand. In particular, experiences of those with different socioeconomic circumstances, limited healthcare access, language barriers, or less capacity to participate in interview-based research may not be fully captured. Although issues of culture, ethnicity, migration, and socioeconomic access appeared in some accounts, the study cannot provide a comprehensive analysis of these experiences or of ethnic inequities in endometriosis care.

The study may have been shaped by self-selection. Participants who chose to take part may have been particularly motivated to share their experiences, may have had especially difficult or meaningful pain journeys, or may have been connected to endometriosis organisations and online networks. As a result, the findings may not reflect the experiences of people who are less connected to support networks, less comfortable discussing pain, or who have different relationships with healthcare and diagnosis.

Another limitation is that the study relied on retrospective accounts. Participants reflected on symptom onset, diagnosis, treatment, healthcare encounters, and changing understandings of pain over time. These accounts are valuable because they show how participants made sense of their experiences, but they may also be shaped by memory, later interpretation, and the meanings participants had developed after diagnosis or treatment. The study therefore does not attempt to verify clinical histories or establish objective timelines of diagnosis and care.

Finally, as a qualitative study, the findings are not intended to be statistically generalisable. Instead, the value of the study lies in its depth, contextual detail, and interpretation of meaning across participants' accounts. The findings offer transferable insights that may be relevant to other people with endometriosis-related persistent pain, healthcare providers, researchers, and support organisations, but they should be understood in relation to the specific sample, context, and interpretive approach of this study.

Future Research

Future research could build on this study by exploring endometriosis-related persistent pain across more diverse populations in Aotearoa New Zealand. Further research could examine the experiences of Māori, Pasifika, Asian, migrant, rural, gender-diverse, and financially constrained people with endometriosis-related persistent pain. Such research would be particularly valuable for understanding how culture, language, geography, health literacy, racism, socioeconomic position, and healthcare access shape recognition, diagnosis, treatment, and support.

Further research is also needed on persistent pain after diagnosis and treatment. Many endometriosis studies focus on diagnostic delay, surgical diagnosis, symptom burden, or treatment outcomes. While these areas remain important, participants in this study showed that diagnosis and treatment do not necessarily end pain or resolve its psychosocial impacts. Longitudinal research could examine how people's experiences of pain, legitimacy, self-understanding, relationships, work, and healthcare engagement change over time after diagnosis, surgery, hormonal treatment, or referral to pain services.

Future studies could also examine models of multidisciplinary and whole-person care for endometriosis-related persistent pain. Participants in this study valued combinations of gynaecological care, pain relief, pelvic physiotherapy, psychological support, counselling, social support, and clear information. Research evaluating integrated care pathways, pain psychology, pelvic health physiotherapy, culturally safe support, peer support, and coordinated endometriosis services would help clarify what

forms of care are most useful, accessible, and acceptable for people living with persistent pain.

There is also scope for further qualitative research on the social and relational dimensions of invisible pain. Participants described managing disclosure, masking symptoms, performing normality, and navigating misunderstanding in workplaces, education, families, friendships, and intimate relationships. Future research could examine how partners, family members, employers, educators, and healthcare providers understand endometriosis-related persistent pain, and how their responses shape the burden or liveability of pain.

Some participants discussed fertility, infertility, reproductive decision-making, and reproductive identity. These issues were considered during analysis, but were not developed as a separate theme because the study focused specifically on the psychosocial experience of endometriosis-related persistent pain. Where fertility appeared in the findings, it was interpreted in relation to pain, uncertainty, healthcare pathways, identity disruption, or future planning. Future research could examine fertility, infertility, and reproductive identity as central areas of inquiry in their own right, particularly in relation to persistent pain, healthcare access, and culturally shaped expectations of reproduction.

Finally, future research could explore the role of self-compassion, acceptance, agency, and identity reconstruction in living with endometriosis-related persistent pain. Participants' accounts suggested that making pain liveable involved not only symptom

management, but also rebuilding self-trust, reducing self-blame, finding supportive relationships, and developing ways to participate in life despite uncertainty. Further research could examine how these processes develop and how they might be supported through psychological, social, and healthcare interventions.

Final Conclusion

The research explored the psychosocial factors, dynamics, and processes that shape the lived experience of endometriosis-related persistent pain among participants in this study, all of whom identified as women in Aotearoa New Zealand. The findings show that persistent pain was not only a physical symptom, but an embodied, emotional, social, relational, and healthcare-mediated experience. Participants' pain was shaped by whether it was believed, how long they waited for care, how others responded to invisible symptoms, how they carried distress and self-doubt internally, and what forms of support helped make pain more liveable.

Across the five themes, the study showed an analytic movement from pain being questioned, to pain being prolonged, socially managed, internally carried, and finally made more liveable through support, relief, and whole-person care. This movement highlights that the burden of endometriosis-related persistent pain is not located only in the body. It is also produced and intensified through normalisation, dismissal, delayed care, fragmented systems, social invisibility, and the pressure to remain functional despite ongoing symptoms.

At the same time, participants' accounts also showed the importance of validation, self-trust, support, pain relief, psychological care, and multidisciplinary approaches. Making pain liveable did not mean accepting pain as inevitable or suggesting that people should simply cope better. Rather, it meant recognising that people with endometriosis-related persistent pain need care that addresses the whole person: the body in pain, the mind carrying uncertainty and distress, the relationships affected by invisibility, and the healthcare systems that can either relieve or intensify suffering.

Ultimately, this study contributes to a more nuanced understanding of endometriosis-related persistent pain as real, embodied, socially situated, and deserving of serious recognition. Improving care requires more than diagnosing disease or treating lesions. It requires listening to people's accounts of pain, believing them before proof is demanded, supporting them through uncertainty, and developing responsive forms of care that make it possible to live more fully with persistent pain.

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Appendix A

Email Requesting Permission to Display Recruitment Materials

Appendix A contains the standardised email sent to healthcare providers, healthcare offices, and endometriosis organisations requesting permission to share the study recruitment flyer by displaying it, sharing it with their networks, or posting it on their social media page. This email outlined the purpose of the research, provided relevant study information, and invited healthcare providers to display or share the recruitment material where appropriate.



Kia ora,

My name is Estie-Lomé Mouton, and I am a Master of Science (Research) student in Psychology at The University of Waikato, supervised by Dr. Cate Curtis. I am conducting a study that has been approved by the Waikato Human Research Ethics Committee (HREC).

The study explores the psychological and social factors that influence the experience of endometriosis-related persistent pain. While the experience of chronic pain is complex, little is known about how these psychosocial factors uniquely shape the lives of people with endometriosis, particularly in New Zealand. The findings of this research will help inform better support, pain management approaches, and multidisciplinary care for people living with endometriosis.

I am writing to kindly ask if you would consider sharing my recruitment flyer with your community — either by displaying it in your clinic, forwarding it to your network, or posting it on your social media/group page. The flyer includes details about the study, who is eligible, what participation involves, and my contact information.

Participation in this study is completely voluntary, confidential, and open to people in New Zealand who have been diagnosed with endometriosis and experience chronic or persistent pain.

If you would like further details or have any questions, please don't hesitate to contact me at em697@students.waikato.ac.nz. My supervisor, Dr. Cate Curtis, can also be contacted at cate.curtis@waikato.ac.nz to verify this research.

Thank you very much for considering this request, and for the work you do in supporting those affected by endometriosis.

Ngā mihi,
Estie-Lomé Mouton
MSc (Research) Student, Psychology
The University of Waikato
em697@students.waikato.ac.nz

Appendix B

Recruitment Materials

Appendix B contains the recruitment materials used to invite potential participants to take part in the study. Figure B1 presents the recruitment flyer sent to healthcare offices for display in relevant healthcare settings. Figure B2 presents the modified recruitment social media tile used by endometriosis organisations when sharing the study through their online platforms.

Figure B1

Recruitment Flyer Sent to Healthcare Offices

Seeking Research Participants



Endometriosis Study

Exploring the experience of chronic pain related to endometriosis

What is this study about?

Living with endometriosis can affect more than just physical health. This study explores how endometriosis-related pain impacts mental health, emotional well-being, and daily life. It aims to understand how psychological and social factors (such as stress, mood, and support) may influence pain experiences and quality of life for people living with endometriosis.

Why is it important?

- contribute to the growing understanding of the psychology of endometriosis-related pain
- support further study and inform the design of effective pain management interventions
- expand knowledge of endometriosis in New Zealand
- help to shape future policies and research priorities

Participant Eligibility:

- Speak English
- Living in New Zealand
- Be 18 years or older
- Clinically diagnosed with endometriosis
- Experiencing persistent pain



Participant Involvement:

Step 1

Contact the researcher for more information

Step 2

Complete a short consent form

Step 3

Participate in an audio-recorded, in-person or online interview that will last 60-90 minutes

For more details, contact:

Estie-Lomé Mouton
Master of Science (Research) student
The University of Waikato
email: em697@student.waikato.ac.nz

Dr. Cate Curtis
Supervisor
email: cate.curtis@waikato.ac.nz

The interview will be held at a time and place that is convenient for you, and all of the information you provide will be treated confidentially.

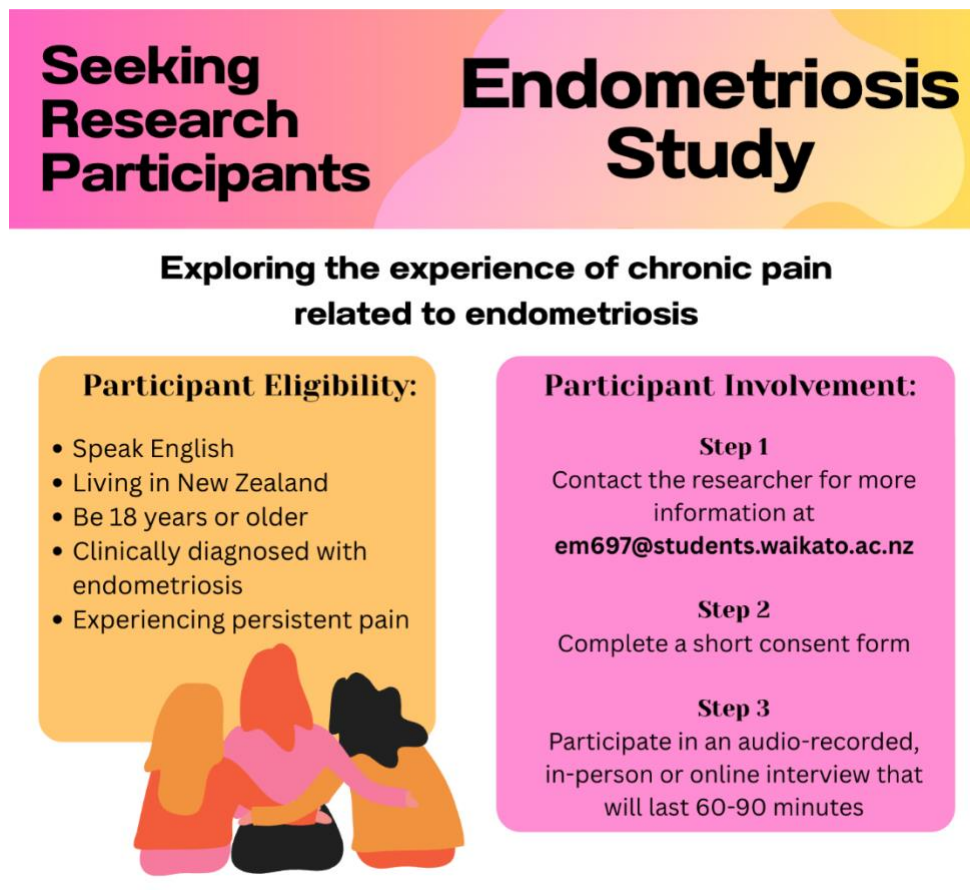
There are low risks involved in the participation in this study.

Approved by The University of Waikato Human Research Ethics Committee
humanethics@waikato.ac.nz

Figure B2

Modified Recruitment Social Media Tile Used for Social Media Posts by Endometriosis

Organisations



Seeking Research Participants

Endometriosis Study

Exploring the experience of chronic pain related to endometriosis

Participant Eligibility:

- Speak English
- Living in New Zealand
- Be 18 years or older
- Clinically diagnosed with endometriosis
- Experiencing persistent pain

Participant Involvement:

Step 1
Contact the researcher for more information at em697@students.waikato.ac.nz

Step 2
Complete a short consent form

Step 3
Participate in an audio-recorded, in-person or online interview that will last 60-90 minutes

Appendix C

Participant Information Sheet

Appendix C contains the participant information sheet provided to potential participants before they decided whether to take part in the study. The information sheet outlined the purpose of the research, what participation would involve, potential risks and benefits, confidentiality procedures, withdrawal rights, data storage, and researcher contact details, as well as, a list of supports.



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Participant Information Sheet

Exploring the experience of chronic pain related to endometriosis

Researcher: Estie-Lomé Mouton

Phone number: +64 27 382 6680

Email address: em697@students.waikato.ac.nz

Level of study: Master of Science (Research)

The experience of chronic or persistent pain is complex because there are many factors that interact with each other to cause different experiences. Little is known about the psychological and social factors that shape the lived experience of endometriosis pain, or whether these factors differ from those observed in other chronic illnesses. This knowledge gap is particularly important in New Zealand, where research on people's experiences of endometriosis remains limited.

You are invited to take part in a study on your experience of persistent pain caused by endometriosis. If you agree to take part in this study, we will go through this information with you and answer any questions. You will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

Voluntary participation and withdrawal from this study

Your participation is voluntary. There are no consequences for declining to participate in this study. You have the right to decline to answer any questions in the interviews that you don't want to. You may withdraw from the research up until two weeks after the interview takes place, by contacting me by email or text message, without any disadvantage to you.

What is the purpose of the study?

The purpose of this study is to investigate how these psychological and social factors impact the experience of endometriosis-related persistent pain. It is important to better our understanding because these factors - including mental health, thinking patterns, and social influences - are linked to higher pain and lower quality of life. The findings of the study can educate people about living with endometriosis and help to develop more effective ways of dealing with pain.

How is the study designed?

I want to talk to people living with endometriosis about their experience of persistent pain. I will conduct the interview in person at a space that is convenient to you in or around Auckland, or via Microsoft Teams. Please let me know how I can meet any needs you have so that you can comfortably participate. The interview will last from 60-90 minutes. If you feel tired or distressed, you can take a break or finish the interview another time.

Who can take part in the study?

You are eligible to participate if you

1. Speak English
2. Live in New Zealand

3. Have been clinically diagnosed with endometriosis
4. Experience chronic pain due to your endometriosis

What would your participation in the study involve?

If you choose to participate, I will contact you to arrange an interview at a time that is convenient for you. Interviews will be audio-recorded and may last from 60-90 minutes. In the interview, you will be asked about your thoughts and experiences regarding your endometriosis-related persistent pain. There will be a focus on the factors that may impact your experience of pain, i.e., mental health conditions, thinking patterns and behaviour, and social influences. You are welcome to have a support person with you during the interview.

What are the possible risks of this study?

There is a low possibility of risk if you choose to participate in the study.

People's experiences of pain are complex and can be challenging to talk about. Interviews will be conducted in a safe, supportive environment. Topics will be approached in a sensitive and non-judgemental manner. **At any point in the interview, you can ask to pause, stop, or have the recording turned off.** Please see the list of supports on page 3.

Discussing chronic pain for an extended period of time might cause fatigue or physical discomfort. Breaks will be offered during the interview, and you are allowed to pause or stop at any time. I will make an effort to ensure in-person interviews are conducted in a location that is physically comfortable. I encourage you to prioritise your privacy and comfort when selecting a location if you are participating in an online interview.

I will ensure the confidentiality of your participation in the study and the information I collect about you, except if you disclose something that causes me to be concerned about a risk of harm to yourself or others. You will be assigned a pseudonym and identifying details will be removed from transcripts. I will ensure the story you share with me is treated respectfully.

What are the possible benefits of this study?

You may find this a valuable opportunity to share your experiences in a safe and supportive environment. Your participation will also contribute to the research in a way that may benefit others.

A greater understanding of how women with endometriosis experience pain may help to guide further research in the field and support the development of more holistic care and better pain management interventions. The ultimate goal is to add to the body of research that will improve outcomes for women living with endometriosis in New Zealand.

Will there be any compensation, or will any costs be reimbursed?

Your contribution to the research will be greatly appreciated; however, there is no compensation offered for participating.

What will happen to your information?

The information collected will be securely stored on password-protected devices or secure servers. You may request and correct any personal information provided to me. In-person interviews will be audio-recorded on my password-protected device, whereas online interviews will be audio-recorded via the platform. There will be no video recordings of the interviews. Recordings will be transcribed using secure automated transcription software (Microsoft Transcription). I will delete any recordings from my devices once they are transcribed.

Any personal information held about you will be deleted at the completion of the research. Only me and my supervisor will have access to the data. The results of the project will be used towards earning my Master of Science degree.

Can you get the results of the study?

A summary of the results will be sent to you, if you wish, at the end of the study.

Who is funding the study?

This research project is not funded by any organisation or institution.

Who has approved the study?

The ethical aspects of this study have been approved by an independent group called the Human Research Ethics Committee (HREC). This committee checks that studies meet ethical standards.

Who do you contact for more information if you have concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact me:

Estie-Lomé Mouton

+64 27 382 6680

em697@student.waikato.ac.nz

Or my supervisor:

Dr. Cate Curtis

cate.curtis@waikato.ac.nz

You can also contact the Human Research Ethics Committee that approved this study on:

humanethics@waikato.ac.nz

Lists of supports

The following services are free and available 24/7.

Lifeline: Call 0800 543 354 (0800 LIFELINE) | www.lifeline.org.nz.

Depression Helpline: Call 0800 111 757 or free text 4202 to talk to a trained counsellor about how you are feeling.

Anxiety NZ: Call 0800 269 4389 (0800 ANXIETY)

For Immediate Support: Call or text 1737 for free, 24/7 counselling if you need immediate help or someone to talk to.

Endometriosis Resources:

- ✧ **Endometriosis New Zealand** - www.nzendo.org.nz
- ✧ **Insight Endometriosis** - www.insightendometriosis.org.nz
- ✧ **Endo Warriors NZ** - <https://www.endowarriorsaotearoa.com>

Appendix D

Consent Form

Appendix D contains the consent form completed by participants before the interview. The form documented participants' informed consent to take part in the study, including consent for the interview to be audio-recorded and for de-identified quotations to be used in the thesis.

Consent form - Exploring the experience of chronic pain related to endometriosis

Please indicate your consent to the following.

I have read and understood the Participant Information Sheet.	Yes ☐	No ☐
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	No ☐
I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study.	Yes ☐	No ☐
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes ☐	No ☐
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time up until two weeks after the interview.	Yes ☐	No ☐
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes ☐	No ☐
I understand my responsibilities as a study participant.	Yes ☐	No ☐
I agree to the interview being audio-recorded.	Yes ☐	No ☐
I agree to the use of automatic transcription software.	Yes ☐	No ☐
I wish to receive a summary of the results from the study. Email:	Yes ☐	No ☐

Declaration by participant: By writing or typing my name in the Signature box, I hereby consent to take part in this study.

Participant's name:

Signature:

Date:

Declaration by a research team member: I have given a verbal explanation of the research project to the participant and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature:

Date:

Appendix E

Demographics Questionnaire

Appendix E contains the demographic questionnaire completed by participants before the interview on Microsoft Forms. The questionnaire collected descriptive information about participants, including age, gender, ethnicity, education, employment status, location, age at diagnosis, and diagnostic history. This information was used to describe the participant sample in aggregated form.

Demographics Questionnaire

The questionnaire takes about **2–3 minutes** to complete. The demographic questionnaire is used solely to describe the participant sample and explore possible trends by age, education, and diagnostic history. All items are optional; participants may skip any question.

1. Age

2. Gender

- ☐ Female
- ☐ Male
- ☐ Non-binary or gender diverse
- ☐ Prefer not to say
- ☐ Other

3. Ethnicity

- ☐ European
- ☐ Māori
- ☐ Asian
- ☐ Pasifika
- ☐ MELAA (Middle Eastern, Latin American, African)

4. Highest level of education

- ☐ Secondary school or equivalent
- ☐ Certificate or diploma
- ☐ Bachelor's degree
- ☐ Postgraduate qualification
- ☐ Other

5. Employment status

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Student
- ☐ Not currently employed

6. Location

- ☐ Auckland
- ☐ Bay of Plenty
- ☐ Canterbury
- ☐ Gisborne
- ☐ Hawke's Bay
- ☐ Northland
- ☐ Marlborough
- ☐ Manawatū-Whanganui
- ☐ Nelson
- ☐ Otago
- ☐ Southland
- ☐ Taranaki
- ☐ Tasman
- ☐ Waikato
- ☐ Wellington
- ☐ West Coast

7. Age of Diagnosis

- ☐ Under 20 years
- ☐ 20-29 years
- ☐ 30-39 years
- ☐ 40 years or older

Appendix F

Interview Guide

Appendix F contains the semi-structured interview guide used during data collection. The guide included questions and prompts relating to participants' experiences of endometriosis-related persistent pain, including pain experiences, emotional wellbeing, cognitive and meaning-making processes, social relationships, healthcare experiences, and treatment or support.

Interview Guide - Semi-Structured Interview on Psychological and Social Factors That
Influence Chronic Pain Related to Endometriosis

Topic	Guiding Questions	Probing Questions
General Pain Experience	Can you tell me about your journey with endometriosis so far? What role does pain play in your journey? How would you describe your pain to someone who has never experienced it?	How did you first realise something was wrong? What was the path to diagnosis like? How does pain affect your daily life?
Mental Health	What impact has living with this kind of pain had on your mental health or emotional well-being? How do you think your mental health affects the way you experience or manage your pain?	In what ways has it influenced your mood, sleep, or outlook on life?
Cognitive Processes & Coping	What kinds of thoughts do you have about managing your pain? How do you usually manage your pain? How often do you find yourself thinking about your pain? Can you share what goes through your mind during a flare-up or painful episode? Knowing that your pain is chronic, how do you make sense of or cope with it?	Are there particular strategies that help? Has it helped? Has your perspective changed over time?
Social Dimensions	Chronic pain isn't always constant. How is life different for you when you're in pain compared to when you're not? Do you think your pain influences your relationships? In what ways has your pain impacted how you see yourself or your identity? Do you share your diagnosis with the people in your life? Do you feel supported by those around you — friends, family, healthcare professionals?	In what way? What has that experience been like?
Treatment and Interventions	What kinds of treatments or supports have you been offered for your pain? What do you think could help you better manage your pain?	What has been helpful? What has not?
Closing/ Summary	What would you like people - whether doctors, researchers, or the public - to understand about endometriosis-related pain? Is there anything else you'd like to share that we haven't talked about?	