Sleep Disturbances in Endometriosis: Healthcare Journeys and Experiences in Aotearoa New Zealand.

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Abstract:

Endometriosis is a chronic condition that affects 1 in 9 people in Aotearoa New Zealand. While its impact on pain and fertility is well-documented, sleep disturbances remain overlooked despite their notable prevalence and contribution to reduced quality of life, exacerbation of physical symptoms and mental distress. A recent Aotearoa New Zealand survey shows a desire among people living with endometriosis to prioritise treatment and symptom management strategies above research into causes or diagnostic imaging, yet no studies to date have investigated how this population manage symptoms such as sleep disturbances in an Aotearoa New Zealand context. To align with these patient-centred research priorities, this study aimed to evaluate current sleep experiences and sleep-related health decisions among those living with endometriosis in Aotearoa New Zealand.

A sample of 374 adults living with endometriosis who had experienced sleep disturbances completed an anonymous mixed-methods online survey. Current sleep disturbances were assessed using the Patient Reported Outcome Measures Information System for Sleep Disturbance 8b short form (PROMIS-SD-8b), and quality of life was assessed using the Endometriosis Health Profile (EHP-5). Sleep-related health decisions, including access to healthcare (type, order, support received), satisfaction and perceived efficacy with healthcare, and self-management strategies were captured. Statistical analyses and development of a patient journey map were used to explore respondents' current sleep health and healthcare decisions. Survey comments captured experiences of these journeys and were analysed using Reflexive Thematic Analysis.

Findings indicate that sleep disturbances represent a significant burden to quality of life of individuals in this sample. Participants actively sought healthcare from multiple providers and sectors. Yet, satisfaction and perceived effectiveness varied, and were often accompanied by frustration. The healthcare encounter was an important aspect of the experience. Additionally, many participants relied on self-management strategies.

The findings highlight unmet sleep-related needs and contribute to a broader understanding of the role of sleep in endometriosis. This study also identifies potential gaps in healthcare for sleep concerns, the need for improved recognition of sleep concerns within healthcare settings, and further research into more effective and comprehensive management strategies for sleep disturbances for people living with endometriosis in Aotearoa New Zealand.

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List of Abbreviations

AoNZ	*Aotearoa New Zealand*
CAM	*complementary and alternative medicine*
CBT-I	*cognitive behavioural therapies for insomnia*
EHP-5	*Endometriosis Health Profile*
GP	*general practitioner*
MELAA	*Middle Eastern/Latin American/African*
NREM	*non-rapid eye movement*
NZD	*New Zealand dollars*
PLWE	*people living with endometriosis*
PROMIS-SD	*Patient Reported Outcome Measures Information System for Sleep Disturbance*
PSG	*polysomnography*
rASRM	*American Society for Reproductive Medicine*
REM	*rapid eye movement*
SONA	*Sleep Opportunity, Need, and Ability*
SPSS	*Statistical Program for Social Sciences*
TA	*Thematic Analysis*

Introduction

Endometriosis is a complex and chronic gynaecological condition that is well known for its symptoms of chronic pelvic pain, dysmenorrhoea and infertility (Johnson et al., 2017), but also by its significant comorbidity (Evans et al., 2018). In medical research, it is defined by the presence of tissue resembling the endometrial lining located outside the uterus, commonly affecting sites such as the ovaries, fallopian tubes, bowels, or bladder (Zondervan et al., 2020). The impact on individuals living with it is vast, and the range of symptoms are well documented to have negative effects on individuals' psychological health (Laganà et al., 2015; Laganà et al., 2017), along with negative effects on the ability to exert energy, socialise, and handle daily personal care tasks (Fleming & Hardy, 2025; Maulenkul et al., 2024).

The symptoms and effects of endometriosis have been described in historical accounts dating back 4,000 years (Nezhat et al., 2012), yet it remains poorly understood today. It is marked by unknown aetiology and no known cure, whereby the lack of scientific knowledge surrounding it has contributed to its description as an "enigma" within medical research (Acién & Velasco, 2013; Nezhat et al., 2012; Yovich et al., 2020). The condition is critiqued as a symbol of historical medical neglect of women's health (Seear, 2009a, 2014).

In Aotearoa New Zealand (AoNZ), endometriosis affects upwards of 10% of individuals, equating to approximately 120,000 people (Ellis & Wood, 2024b). Accurately calculating prevalence in AoNZ is challenging due to well-known barriers to diagnosis, resulting in significant delays that can span up to 10 years (Ellis & Wood, 2024a). In AoNZ, endometriosis also represents a great challenge to manage from the perspective of healthcare providers (Ellis et al., 2024), and has been shown to have a great cost to the national healthcare system (Tewhaiti-Smith et al., 2025).

Much of the research surrounding endometriosis has primarily focused on understanding, treating and managing pain. However, among the far-reaching and contributing symptoms, sleep disturbances are increasingly recognised as a common and meaningful yet underexplored aspect of the condition. Sleep disturbances are highly prevalent amongst this population, with prevalence estimates reaching 70%

(Zhang et al., 2024), and are increasingly understood as contributing to endometriosis-associated pain and mental distress (Baldi et al., 2025; Sumbodo et al., 2024). Nevertheless, little is known about how individuals experience, manage or navigate their sleep disturbances in real-world contexts. A small number of studies have examined the healthcare journeys of individuals with endometriosis, yet even fewer have explored how sleep concerns are being addressed. Therefore, a gap remains in understanding how sleep disturbances are experienced, responded to, and managed within everyday life and in healthcare. In addressing this identified research gap, the present study aims to explore how sleep is experienced within modern, holistic conceptualisations of sleep, and to investigate what characterises the sleep-related healthcare journeys for people with endometriosis in AoNZ.

Chapter One: Literature Review

1.1 Endometriosis

1.1.1 A Chronic Condition

Endometriosis is a benign, chronic gynaecological condition characterised by endometrial-like tissue found outside the uterine cavity (Johnson et al., 2017). These displaced tissues form lesions that are located in areas surrounding the uterus, including within the muscular walls of the uterus and at sites near the uterus, such as the ovaries or fallopian tubes. However, these lesions have also been discovered at more distant sites, such as the bowels, bladder, and, more recently, the diaphragm and lungs (Acién & Velasco, 2013; Pais & Almeida-Santos, 2023).

In response to fluctuating hormones during a menstrual cycle, endometriosis lesions inflame and bleed, which generate significant local and systemic inflammation and have a significant impact on the body (Zondervan et al., 2020). The resulting symptoms are often non-specific, affect multiple body systems, and vary widely between individuals (Zondervan et al., 2020). The condition is most often characterised by the symptoms relating to chronic pain, which can present as chronic pelvic pain, dysmenorrhea (painful periods), dyspareunia (painful intercourse), dyschezia (painful defecation), dysuria (painful urination), fatigue, and infertility (Johnson et al., 2017; Zondervan et al., 2020).

Endometriosis is a highly prevalent condition that primarily affects women and girls of reproductive age, as well as those presumed female at birth, with the vast majority being between 25 and 45 years old (Smolarz et al., 2021). Epidemiological estimates suggest that approximately 10% of cisgender women and girls of reproductive age live with endometriosis (Shafrir et al., 2018), equating to an estimate of 176 million people worldwide (Adamson et al., 2018). Prevalence data in Aotearoa New Zealand (AoNZ) are limited, although longitudinal evidence indicates that approximately 7.8% of women in a cohort of 429 participants had received a diagnosis of endometriosis by age 38 (Righarts et al., 2018). In Australia, a country with social and economic wealth and development similar to AoNZ, the estimated prevalence of endometriosis is approximately 11%, equating to approximately 1 in 9 women (Rowlands et al., 2021).

Prevalence estimates remain difficult to accurately determine because data are not consistently reported across transgender and gender-diverse (Adler et al., 2025), and are poorly reported across ethnic groups, internationally and within AoNZ (Ellis & Wood, 2024a; Zondervan et al., 2020).

1.1.2 Incompletely Understood and Contested

The current literature on endometriosis shows that it occupies an ambiguous and contested position within medicine and healthcare. The condition is characterised by ontological uncertainty, limitations in classification and measurement, and ongoing challenges in its management (Hudson, 2022; Zondervan et al., 2020).

Firstly, the aetiology of endometriosis is not completely understood. There are multiple, often competing, and incomplete theories about how the condition develops and progresses. Decades of pathophysiological research have attempted to explain how endometriosis develops, yet this remains largely unknown (Gruber & Mechsner, 2021; Lamceva et al., 2023). The initial, and most accepted theory of pathogenesis to date was proposed by Dr Sampson in 1937, suggesting a process of "retrograde menstruation" was the reason for its existence (Sampson, 1922; as cited in Smolarz et al., 2021). Retrograde menstruation is a process in which endometrial tissue travels backwards and escapes the uterus via the fallopian tubes during normal uterine contractions of menstruation. This was thought to be the mechanism by which these endometrial-like tissues present outside the uterus. Sampson proposed that, once outside the uterus, the tissue attaches to the wall of the peritoneal cavity and establishes blood flow, which responds to fluctuations in menstrual-cycle hormones. However, this 'reflux' of menstrual blood has since been found to be a common event among all women, occurring in approximately 80% of menstruating women (D'Hooghe & Debrock, 2002; Tosti et al., 2015), yet not all women have endometriosis; endometriosis appears in some cisgender men (Rei et al., 2018) and in some women after a hysterectomy (Lamceva et al., 2023). This, and many other similar theories, attempt to explain the pathology, yet none have yet explained the vast heterogeneity of

symptoms and contain unexplainable flaws, leaving their understanding inconclusive (Wang et al., 2020).

Current literature suggests that retrograde menstruation may be involved in the initial transport of endometrial tissue into the peritoneum, although many mechanisms and processes—such as altered immunological factors, naturally fluctuating hormones like oestradiol, epigenetic changes, localised inflammation, and immune system dysfunction—contribute to oxidative damage and the development of adhesive, proliferative endometriosis lesions that resist the suppressive effects of peritoneal fluid (Imperiale et al., 2023; Tosti et al., 2015). Recent research also suggests that the condition may arise and be perpetuated by a combination of genetic and environmental factors (Caporossi et al., 2021; Montgomery et al., 2020; Pais & Almeida-Santos, 2023; Zhang & Ma, 2021), although no consensus on a causal or pathogenic mechanism has been established.

It has also been recognised that although endometriosis is a benign disease, it behaves similarly to cancer (Kvaskoff et al., 2021). Endometrioses proliferation and invasive nature are physiologically similar to those of many cancers, and some researchers suggest it should be treated within medical spaces as such (Kvaskoff et al., 2021; Nezhat et al., 2012). The incomplete understanding of this condition has left many questions unanswered in research, contributing to its description as a medical mystery (Hudson, 2022).

1.1.3 Diagnosis and Management Challenges

Classifying the condition emerges as another point of contention. It is argued that no single classification system adequately categorises endometriosis (Hudson, 2022; Johnson et al., 2017), which further positions endometriosis as problematic. The most widely employed system for classifying endometriosis assigns stages based on the extent and depth of the lesions, as well as the quantity of scarring and/or adhesive lesions present. Stage I (‘mild’) progresses until Stage IV (‘severe’) (American Society for Reproductive Medicine (rASRM), 1997). The contentedness arises because these stages (Stage I to IV) have long been known not to correlate with the condition's

symptomatology (Vercellini et al., 2007). A recent review found no difference in symptom intensity across these stages (Alves et al., 2025). This highlights endometriosis as a complex condition but also brings to light the challenges that arise in detecting and diagnosing it.

Diagnosing endometriosis poses substantial challenges. Endometriosis is often confused with other conditions affecting the pelvic area, such as appendicitis and irritable bowel syndrome, making it difficult to initially assess in clinical settings (As-Sanie et al., 2019). Currently, the gold-standard method for diagnosing endometriosis involves surgery. This is often done via laparoscopy 'keyhole' surgery, in which suspected areas are inspected, and suspicious tissue is biopsied and examined (Gratton et al., 2022).

At present, there are no validated, non-invasive biomarkers (naturally occurring molecules, genes, or characteristics by which a disease can be identified) capable of reliably diagnosing the condition from serum, plasma, urine, or other objectively measured biological samples (As-Sanie et al., 2019; Smolarz et al., 2021). Promisingly, advances in imaging technology, such as highly specific transvaginal ultrasound and magnetic resonance imaging, are increasingly being able to detecting some stages of endometriosis without the need for invasive surgery, however, they are currently not reliable or adequate to be considered as a definitive diagnostic method (Crump et al., 2024; Nisenblat et al., 2016; Tian et al., 2020). Therefore, surgery still remains the most definitive and superior approach to diagnosing endometriosis.

Diagnostic surgeries for endometriosis have been the subject of discussion in recent years as they are invasive, difficult to access and have risks and complications associated with them (Shafrir et al., 2018; Simko & Wright, 2022). The surgery itself is also very difficult to perform and requires a highly skilled surgeon, described as an "acquired art" (Redwine, 2003, p. 65). This means that even if an individual has access to an investigative surgery, the accuracy of the diagnosis depends on the surgeon's experience and skill (Shafrir et al., 2018). Receiving a second opinion from another surgeon has been shown to change the diagnosis in over half of participants, as seen in a recent European study (Durant des Aulnois et al., 2025).

Consequently, individuals living with endometriosis often face lengthy diagnostic journeys, with delays typically averaging between seven and nine years since symptom onset (Ghai et al., 2020). Recent evidence from AoNZ also indicates that, although the time to diagnosis has improved, diagnosis still occurs nearly 10 years after symptoms first appear, with an average delay of about nine years (Ellis & Wood, 2024a; Tewhaiti-Smith et al., 2022). To lessen dependence on surgical confirmation and to address diagnostic delays, clinical guidelines in Australia, developed by *The Royal Australian and New Zealand College of Obstetricians and Gynaecologists* (2025), have recently been revised to include a more subjective approach to diagnosis, not relying on surgery as heavily, and allowing symptoms to be managed by a general practitioner (GP). However, AoNZ clinical guidelines have not yet been updated to reflect this new approach. The clinical guidelines for diagnosing endometriosis in AoNZ are now considered outdated (Ellis et al., 2024; Endometriosis New Zealand, 2025).

Once individuals are diagnosed with or suspected of having endometriosis, managing the condition is similarly complex. There is currently no cure, therefore most treatments mainly focus on controlling symptoms rather than eliminating the disease. As the endometriosis lesions respond to fluctuations of reproductive hormones, stabilising these fluctuations with hormone therapy and hormone-suppressing medication helps to suppress the lesions' growth and the inflammatory processes that result. As such, first-line medical treatments for managing symptoms of endometriosis usually involve medications such as non-steroidal anti-inflammatory drugs and hormone therapy (Rafique & Decherney, 2017; Smolarz et al., 2021).

Surgical removal of the endometriosis tissue is also commonly used as a management option; however, evidence of its long-term success remains inconclusive, as lesions frequently recur or are incompletely removed (Bafort et al., 2020; Chapron et al., 2019). Moreover, removing the lesions doesn't consistently reduce the symptoms (Simko & Wright, 2022). To demonstrate the uncertainty surrounding surgical removal of lesions, recent research in AoNZ finds that 76 of 450 surgeries were performed due to suspected recurrence of endometriosis tissue, and that the recurrence of endometriosis in these repeat surgeries was confirmed in over half of these instances (Paterson et al., 2024). Managing persistent symptoms of endometriosis is further

complicated by the fact that many PLWE experience central sensitisation. Central sensitisation is an adaptation of the nervous system that occurs after repeated nerve stimulation persists over time (Grundström et al., 2019). In PLWE, central sensitisation manifests as persistent pain, even after successful surgical removal of the lesions (Raimondo et al., 2023; Stratton & Berkley, 2011).

Both healthcare providers and PLWE recognise and acknowledge the complexity of managing this condition within clinical settings (Evans et al., 2022; Fallon et al., 2024). These challenges are relevant because they contribute to the financial burden of endometriosis on the AoNZ healthcare system. A recent cost analysis of endometriosis conducted in AoNZ estimates that the condition incurs annual costs ranging from 16.9 to 23.7 billion New Zealand Dollars (NZD) (Tewhaiti-Smith et al., 2025).

1.2 The Lived Experiences of Endometriosis

1.2.1 Well-being Impacts

Endometriosis significantly affects all areas of a person's life, representing a significant burden. Research consistently demonstrates the negative impacts on physical, mental, emotional and social well-being (Fleming & Hardy, 2025; Maulenkul et al., 2024; Young et al., 2015). For example, many studies demonstrate that PLWE experience poorer health-related quality of life than controls (Álvarez-Salvago et al., 2020; Evans et al., 2018; Facchin et al., 2021). Depression and anxiety are also highly associated with the condition (Laganà et al., 2017; van Barneveld et al., 2022; Wang et al., 2021) and are likely a direct impact of the symptoms associated with the condition, such as pain (Laganà et al., 2015).

The lived experience of individuals with endometriosis has been characterized as a challenge to one's sense of identity, body image, concerns regarding being a burden to others, sexual distress, and strain within intimate relationships (Cole et al., 2021; el Hadad et al., 2024; Sullivan-Myers et al., 2023). Furthermore, people with the condition frequently have difficulty exercising for long periods, keeping up with tasks around the home, and struggle with persistent and chronic fatigue (Szypłowska et al., 2023). In particular, chronic pain associated with endometriosis is shown to impair an

individual's ability to perform everyday activities, such as walking, standing, sitting, defecating, and sleeping (Leuenberger et al., 2022). Importantly, the impacts on well-being exceed those associated with other chronic issues. Recent studies have demonstrated that impairments in quality of life were greater amongst those with endometriosis, compared to those with heart disease, breast cancer, diabetes, and rheumatoid arthritis (Rempert et al., 2024; Szypłowska et al., 2023).

The limitations of endometriosis contribute to economic impacts too. Research has demonstrated that as the severity of endometriosis symptoms increases, work-related productivity and hours worked decrease (Soliman et al., 2017). In AoNZ, the cumulative financial burden to an individual with endometriosis, inclusive of health care costs, productivity losses, and treatment-related expenses, has recently been estimated at approximately $174,130 NZD per year (Tewhaiti-Smith et al., 2025). Accordingly, endometriosis has understandably been described as a condition that individuals organise their lives around (Zondervan et al., 2020).

1.2.2 A Societally Invisible Issue

Endometriosis has been frequently referred to as the “missed” or “enigmatic” disease, due to its longstanding gaps in knowledge regarding its aetiology, diagnosis and management (Nezhat et al., 2012; Overton & Park, 2010; Seear, 2014, p. 61). Feminist scholars have long highlighted that the gaps in knowledge around endometriosis are shaped not only by a lack of biological understanding, but also by long-standing cultural narratives about a woman’s gendered role in society (Jones, 2015; Nezhat et al., 2012; Seear, 2014). For example, Jones (2015) describes the influence of the ‘wandering womb’ as a narrative that pathologises women’s bodies when they do not conform to expectations of reproduction and motherhood. This narrative has been argued to shape how symptoms are interpreted in research and in healthcare. In this view, subjective symptoms such as pain or fatigue are often considered less valid in medical practice or research, especially compared to concerns related to fertility or childbearing (Samulowitz et al., 2018; Young et al., 2019).

The long-standing gaps in knowledge about endometriosis contribute to its characterisation as contested and partially visible within healthcare and society. This is because it remains largely invisible to the public imagination (Hudson, 2022). This is exemplified in research by findings showing that individuals with endometriosis are often made to decide between pursuing fertility or symptom relief, as the treatments often run counter to one another (Culley et al., 2013).

Feminist scholars also highlight how women's pain in particular has historically been reframed as emotional or psychological, reflecting the legacy of "hysteria"- the now discredited psychiatric disorder that formed from medicine's neglect of women's bodies as legitimate (Jones, 2015; Ussher, 2011). While hysteria is no longer a formal diagnosis, the patterns that define it persist in modern healthcare contexts for PLWE. This has been proposed as particularly relevant in the context of endometriosis, where women's concerns persist beyond medical explanation or are uncontrollable (Young et al., 2019).

Research and government policy changes have been made to address some of this historical neglect. For example, the *Women's Health Initiative* in the United States, and the *Women's Health Strategy* in AoNZ (Minister of Health, 2023). However, Young et al. (2019) argue that the priorities of research for PLWE still reflect historical, oppressive, gendered assumptions in relation to endometriosis. For example, a recent study examined male partners' perspectives on endometriosis (Culley et al., 2017). This example has been interpreted as indicative of an ongoing emphasis on men's perspectives and experiences for the betterment of men, rather than on centring the lived experiences, priorities and unmet needs of the women who are directly affected by the condition (Young et al., 2019). Young et al. (2019) also highlight that further research is needed to adequately address these long-standing issues. These concerns are supported by researchers in AoNZ alike (Ellis & Wood, 2024b).

Considering the extensive impact of endometriosis on individuals' quality of life, as well as on women overall, research continues to focus mainly on a limited set of symptoms, such as fertility and pain. This narrow focus may neglect other relevant, significant, and underexamined symptoms that influence individuals' burden.

1.3 Sleep Disturbances in Endometriosis

It is increasingly recognised that sleep-related issues are a common feature of endometriosis. A recent meta-analysis found that sleep disturbances are indeed prevalent among PLWE (Zhang et al., 2024). Data from over 2,500 individuals were used to estimate a combined worldwide prevalence of sleep disturbances in PLWE to be over 70%. Individual studies included in this meta-analysis often report even higher estimates in some samples, ranging from approximately 80% to over 90% (Davie et al., 2020; de Souza, Villela, et al., 2023).

Sleep-related issues are also more common in those with endometriosis than in those without. This is shown in multiple case-control studies (Ramin-Wright et al., 2018; Sumbodo et al., 2024), and is especially identified among those with more severe symptoms compared to those with less severe symptoms. For instance, in a study of 665 individuals, poor sleep quality was more strongly associated with higher pain symptoms than with lower ones (Chaichian et al., 2024). Comparisons with other chronic illness populations further highlight the extent to which sleep difficulties affect PLWE. The prevalence reported by Zhang et al. (2024) exceeds pooled estimates reported in other conditions, such as cancer (60.7%) (Al Maqbali et al., 2022) and irritable bowel syndrome (37.6%) (Wang et al., 2018), suggesting that sleep problems are a particularly prominent feature of endometriosis.

Sleep disturbances that are experienced by PLWE are often described in terms of their lived impact. For example, qualitative literature consistently portrays these experiences as disrupting social relationships, impacting functioning at work and in school, and negatively affecting mood, emotional health, physical ability, and the ability to perform behaviours such as self-care (DiBenedetti et al., 2020; Spyrelis et al., 2024). Quantitative findings also demonstrate the significance of these impacts, with evidence linking sleep disturbances among PLWE to poorer quality of life, increased depressive symptoms, and greater pain (Arion et al., 2020; Chaichian et al., 2024).

1.4 Sleep Health and Its Relevance to Endometriosis

Before critically examining how sleep and endometriosis are related, it is essential to first unpack the concept of sleep and its vital role in health and well-being. The following sections provide an overview of the functions of sleep in relation to health and well-being, then conceptualises 'sleep health' based on current research. Finally, the relationship between sleep and endometriosis is explored.

1.4.1 The Physiology of Sleep

The phenomenon of sleep has been characterised in varied ways within the scientific literature. Behaviourally, sleep is defined by a reversible state of perceptual disengagement from the environment, which is typically characterised by closed eyes, resting posture, and reduced mobility (Carskadon & Dement, 2011). However, sleep is also defined according to its physiologic characteristics, such as collection of tightly regulated physiologic processes associated with measurable changes across multiple biological systems, including changes in brain wave activity, heart rate, respiration, and autonomic function (Tubbs et al., 2019). Much of the scientific understanding of sleep, therefore, emerges from the physiological research examining the biological structure and regulation of sleep.

Sleep architecture refers to the structural organisation of sleep across the night. Normal adult sleep comprises two primary states: non-rapid eye movement (NREM) and rapid eye movement (REM) sleep, which alternate during the night in a cycling fashion (Carskadon & Dement, 2011; Foster, 2020). NREM is divided into three stages, each of which represents progressively deeper sleep, whereas REM represents a single stage of sleep uniquely characterised by rapid movements of the eyes and specific neural activity patterns.

In healthy adults, sleep typically cycles between NREM and REM stages every 90-110 minutes (Rowley & Badr, 2022). Stage 1 NREM represents light sleep, whereas Stage 3 represents deep or slow-wave sleep. As sleep deepens across NREM stages, brain-wave activity becomes slower and lower in frequency (generally as low as 0.5–2 Hz) and greater in amplitude (typically reaching >75 μV in Stage 3 NREM). Stages of

NREM sleep collectively account for roughly 80% of sleep time (Rowley & Badr, 2022). REM sleep is popularly characterised by the time that dreaming occurs. But it is also characterised by a temporary, near-total skeletal muscle paralysis, and brain activity that resembles wakefulness (Carskadon & Dement, 2011). REM sleep accounts for roughly 20% of a sleep cycle (Rowley & Badr, 2022).

Sleep and wakefulness are two distinct behavioural states, each marked by characteristic patterns of neural activity, physiological function and behaviour. The regulation of these states is modulated by the interaction of two primary processes: the homeostatic process and the circadian timekeeping system (Saper & Fuller, 2017). The homeostatic process reflects the accumulation of sleep pressure, which builds up the longer one is awake. This sleep pressure mechanism manifests as electrical activity in the brain, which is determined by mutually excitatory and inhibitory circuits (Zielinski et al., 2016). The sleep pressure homeostatic mechanism is one of the regulatory mechanisms that contributes towards maintaining an appropriate balance between periods of sleep or wakefulness**.**

An additional mechanism that regulates sleep and wakefulness is the internal circadian time-keeping system. The circadian system is coordinated by a central, master clock, situated in the brain's suprachiasmatic nuclei (SCN), which regulates all circadian rhythms and peripheral circadian clocks found in other organ systems throughout the body (Foster & Kreitzman, 2014; Tubbs et al., 2019). To keep in step with the external light/dark cycle of the sun, the circadian master clock synchronises with external, environmental cues, such as light exposure (Foster, 2020; Saper & Fuller, 2017). Through these mechanisms, the circadian system determines when we sleep, as well as waking function, and to some extent, sleep architecture (Foster, 2020; Tubbs et al., 2019).

1.4.2 Sleep for Health and Well-being

The literature views sleep as a vital, non-negotiable component of health and well-being, with broad implications for physical, psychological, and social functioning (Grandner, 2017; Vorster et al., 2024). Although sleep serves many functions, this

thesis emphasises its effects on health and well-being, as these are crucial outcomes particularly relevant in the context of chronic conditions such as endometriosis, where they closely reflect the challenges faced by those living with the condition.

Sleep has historically been regarded as a passive process whose purpose was solely to conserve energy; however, this view has been redefined in recent years to reflect that it is an active contributor to health and well-being (Buysse, 2014). For example, sleep's role in conserving energy goes beyond merely reducing physical activity and the subsequent need for nutrient intake. Instead, energy is conserved through active biological processes that are upregulated during sleep and properly allocate resources for restorative functions, such as tissue repair and cellular regeneration (Schmidt et al., 2017; Zielinski et al., 2016). This shows that sleep is an active process, not just a reduction in metabolic rate due to inactivity, as previously thought.

It is evident that sleep acts as a multi-system regulator of health, with a wide range of effects that cannot be simplified to a single function (Zielinski et al., 2016). For instance, sleep is intrinsically connected to immune system function by its role in facilitating, modulating, and strengthening the biological processes that a healthy immune system relies on (Asif et al., 2017; Irwin & Opp, 2017). Sleep also plays a role in regulating hormones that help manage the menstrual cycle (Alzueta & Baker, 2023), and is essential for learning and memory by facilitating the storage of day-to-day memories in the brain, known as memory consolidation. Sleep's role is also vital in language processing, creativity, attention and problem-solving, which support everyday functioning (Simon et al., 2022).

Regarding mental health and well-being, sleep is shown to have a causal relationship, whereby improvements in sleep are associated with improvements in mental health (Scott et al., 2021). Sleep fosters emotional regulation by recalibrating neural networks involved in stress and mood control, which allows for emotional processing and regulation (Goldstein & Walker, 2014; Lefter et al., 2022). Ultimately, sleep's role in predicting mental health and well-being outcomes has been deemed as important as exercise and diet (Wickham et al., 2020).

Conversely, when sleep is disrupted, disturbed, dysfunctional or disordered, it has a wide range of downstream effects on health and well-being. For example, poor sleep is associated with an increased risk of obesity, diabetes, neurocognitive dysfunction, cardiovascular disease, mood disorders such as depression and anxiety, as well as poor mental well-being (Grandner, 2017; St-Onge et al., 2025).

1.4.3 Sleep Health as a Multi-Dimensional Concept

Historically, sleep has been viewed in relatively narrow terms, often defined simply by the presence or absence of clinically diagnosable sleep disorders, such as insomnia or sleep apnoea. Measurements of sleep have also historically been conducted using a single indicator, such as hours slept per night, or by objective physiological signals, such as brain activity and muscle movements obtained through polysomnography (PSG) in laboratory settings. Although PSG is regarded as the gold standard measurement for assessing the physiological aspects of sleep, and is crucial for diagnosing many sleep disorders, its limitations in capturing sleep in a comprehensive manner have been widely recognised (Buysse, 2014; Foster, 2020; Grandner, 2017; St-Onge et al., 2025). For instance, a PSG captures sleep at a single point in time; it does not account for subjective sleep satisfaction and is usually conducted in an artificial environment, which can influence the results. The dilemma is that sleep can be measured both objectively and subjectively, where both methods are valuable and important for understanding sleep. Yet, subjective measures have historically been given less emphasis.

In recent years, sleep science has undergone a conceptual shift, viewing sleep as a multidimensional construct (Buysse, 2014; Hale et al., 2020; Vorster et al., 2024). In Buysse's (2014) seminal paper, sleep was reframed as "a multidimensional pattern of sleep-wakefulness, adapted to individual, social, and environmental demands, that promotes physical and mental wellbeing" (p.12), rather than merely the absence of a sleep disorder. This proposed conceptualisation has been accepted and expanded to reflect a deeper understanding of the idea and importance of 'sleep health' (St-Onge et al., 2025; Vorster et al., 2024).

‘Sleep health’ now encompasses eight interrelated dimensions that each contribute toward health and well-being independent of one another (Vorster et al., 2024). These dimensions include appropriate sleep duration per a 24-hour period, continuous and uninterrupted sleep, adequate alertness in the day, appropriate placement of sleep within a 24-hour period, consistent and stable patterns of sleep and wakefulness over time, subjective satisfaction of sleep in hindsight, an absence of sleep disorders, and appropriate breathing while asleep (Vorster et al., 2024). The combination of objective and subjective assessments captures the holistic experience of sleep, providing deeper insight into how individuals interpret and respond to it.

Importantly, disruptions to any of the sleep health dimensions are associated with negative health and well-being outcomes, independent of one another (Vorster et al., 2024). For example, inadequate sleep duration – whether too few or too many hours – is associated with adverse health outcomes, such as obesity, cardiovascular disease, and mortality risk (Chaput et al., 2020). Or, for instance, sleep satisfaction—defined as an individual’s evaluation of how “good” or “poor” their sleep was upon waking—is found to exhibit a greater effect on mental health and well-being outcomes than sleep duration and other healthy behaviours such as exercise and fruit and vegetable consumption (Wickham et al., 2020).

1.4.4 Sleep Health in a Social-Ecological Model of Well-being

Each dimension of sleep health is influenced by various personal mediating factors, such as behaviours (e.g., avoiding alcohol, caffeine, or late-day light exposure), genetic factors (e.g., age), and cognitive factors (e.g., personal beliefs) (Baranwal et al., 2023). However, in light of sleep disparities that are apparent across populations from different racial, social, and environmental contexts, modern researchers acknowledge that sleep health dimensions are also influenced by a myriad of broader factors (Grandner, 2017; Hale et al., 2020; St-Onge et al., 2025). The socioecological model of sleep health is a framework that situates the dimensions of sleep health within the broader individual, social, and societal factors that can influence it (Grandner, 2017). For example, sleep health is influenced not only by an individual’s age, occupation,

culture, or socioeconomic status, but also by the place that they live, the public policies in play, the quality of their interpersonal relationships, the amount of financial stress they are under or their beliefs around sleep (Grandner, 2017; Hale et al., 2020).

Understanding sleep health within a multidimensional, socio-ecologically embedded framework is important in the context of chronic illness, as it highlights how negative sleep health outcomes may result from individual, social, and societal factors, and how these outcomes can manifest in many different, subtle, and fluctuating ways. In a population who are already experiencing complex, often normalised and under-recognised symptoms, sleep disturbances may therefore be particularly vulnerable to being overlooked in clinical and research settings.

1.4.5 The Relationship Between Sleep Disturbances and Endometriosis

The literature on sleep disturbances in PLWE demonstrates multiple plausible mechanisms linking their relationship. A recent review article discusses the significant association between sleep disturbances and endometriosis and highlights how pain may serve as a potential mediator of sleep disturbances in PLWE (Sumbodo et al., 2024). The mechanism between pain and sleep is well-established in the literature on chronic pain. There is strong evidence showing a bidirectional relationship between pain and sleep disturbances, demonstrating that pain can disrupt and conversely, poor sleep can heighten the experience of pain (Andersen et al., 2018; Finan et al., 2013; Koffel et al., 2016).

In research involving PLWE, pain appears to disrupt sleep in similar ways. A large body of research demonstrates associations between greater pain and poorer sleep-related outcomes (Chaichian et al., 2024; de Souza, Villela, et al., 2023; Ramin-Wright et al., 2018). Collectively, these studies demonstrate that the intensity and duration of pain influence the disruptions to sleep. For example, de Souza, Vilella, et al. (2023) found that PLWE with more intense and longer-lasting pain had a higher prevalence of insomnia than those with less intense and shorter periods of pain. This relationship also appears to be bidirectional in PLWE. A study by Nunes et al. (2015) demonstrated that sleep restriction heightened the sensitivity pain in PLWE, while simultaneously lowering

their tolerance to endure pain. These findings importantly demonstrate how sleep disturbances may act as both a perpetuating amplifier and a result of pain in PLWE, rather than simply a side effect of the condition.

While pain appears to represent the primary mechanism between sleep disturbances and endometriosis, it is not the only identified factor in the literature. Sleep disturbances have been found to occur in endometriosis, independent of pain experiences (Facchin et al., 2021) and independent of disease stage (Ramin-Wright et al., 2018). Psychological factors have also been identified as relevant contributors, as demonstrated in a recent study by Pickup et al. (2024). Pickup et al. (2024) find that PLWE who express worry and fear about the progression of the disease, such as concerns about infertility or worsening symptoms, are associated with sleep disturbances, independent of pain.

Beyond pain and psychological health linking sleep disturbances to endometriosis, additional biological and contextual factors have been proposed, although these have not yet been extensively examined in individuals with endometriosis. For example, Sumbodo et al. (2024) and Leuenberger et al. (2022) draw on research from other fields to propose that processes such as inflammation, hormonal changes during the menstrual cycle, hormonal and pain medications, and additional co-morbid pain conditions may also contribute to the manifestation of sleep disturbances in PLWE (e.g., Baker & Lee, 2018; Irwin, 2019; Shaver & Iacovides, 2018). Despite well-established associations and other plausible mechanisms linking endometriosis and sleep disturbances, a considerable portion of the existing literature has concentrated on documenting the impacts. In contrast, fewer studies have investigated how individuals manage these issues.

1.4.6 Sleep-Related Management in the General Population

In the general population, sleep disturbances have a limited range of treatments within healthcare settings. If a patient were to present to a medical professional with sleep concerns, they may be offered a combination of ‘sleep hygiene’ education, cognitive behavioural therapies for insomnia (CBT-I), or medication (BPAC NZ, 2017).

Sleep hygiene involves behavioural advice such as adjusting caffeine intake, exercise, sleep timing and regularity, and adjusting environmental factors such as light, noise, and temperature. This is typically discussed in relation to healthy sleep. However, research indicates that sleep hygiene education alone is not sufficiently effective for treating sleep-related issues such as insomnia (Ruan et al., 2025).

CBT-I is a form of psychotherapy designed to treat insomnia using a mixture of behavioural training such as sleep hygiene education, sleep restriction, relaxation techniques, and cognitive therapy. It has been found to be effective for treating insomnia both acutely and long-term, as seen in meta-analysis study by Trauer et al. (2015). However, remission rates are low, with a study showing nearly 40% of participants not successfully achieving remission after treatment (Galbiati et al., 2019).

Medication is also a common treatment for sleep issues. Among the commonly prescribed pharmacological interventions for sleep issues are hypnotic and sedative medications such as benzodiazepines, zopiclone, and doxylamine; however, these medications are not well tolerated, safe or suitable for long-term use, and many available options are not particularly beneficial (De Crescenzo et al., 2022). Melatonin is another commonly used medication, yet evidence on its effectiveness remains poor (Buscemi et al., 2006). Consequently, there are limited treatment options available within healthcare. Clinicians are therefore recommended to offer a combination of therapies rather than a single therapy for treating (Edinger et al., 2021).

There is a limited body of research tracking the process by which patients manage their sleep-related issues. For example, one study maps the journey that patients with insomnia took to manage their condition, including points at which they had accessed healthcare professionals, points at which they had used self-management strategies, and experiences along the way (O'Regan et al., 2023). Another European study similarly tracked the healthcare journeys and associated experiences of participants suffering from narcolepsy and idiopathic hypersomnia (Vesinurm et al., 2025). Both examples demonstrate that sleep-related care often involves misdiagnosis in the early stages and frequent trial-and-error with many treatments, highlighting unmet needs in this area.

1.5 Healthcare Journeys in Endometriosis

In the context of endometriosis, there remains a particularly limited understanding of how PLWE manage, navigate, and address sleep disturbances within healthcare. Research on specific healthcare journeys for PLWE is very limited. For example, one qualitative study describes PLWE visiting healthcare providers for their symptoms, and suggests that these pursuits are strongly influenced by symptom severity (Metzemaekers et al., 2021). Broader qualitative research on the experiences of healthcare for PLWE reveals several themes.

Firstly, many PLWE experience frustration, dissatisfaction, stigma, and occasional psychological distress in their encounters with healthcare (Evans et al., 2022). These experiences involve the perception that healthcare providers are unprepared to provide adequate care (Young et al., 2017). Consequently, many PLWE consult with multiple doctors before feeling their needs are met (Evans et al., 2022; Young et al., 2015), and feel that their healthcare providers overlook their losses (Peterson et al., 2023).

Secondly, in the interactions between PLWE and their healthcare providers, communication challenges appear to be common. Studies find that the subjective nature of endometriosis-associated symptoms, such as pain, is suggested to diminish clear description and communication of the issues, which results in frustrating interactions such as symptoms being normalised, overlooked and dismissed (Bullo, 2020; Bullo & Weckesser, 2021). On the other hand, positive healthcare interactions characterised by support, active listening and empathy are shown to significantly improve experiences of the healthcare encounter, by offering hope, validation and relief to PLWE (Fernley, 2021; Grundström et al., 2023).

Lastly, self-advocacy and assertiveness have long been highlighted as vital parts of the healthcare experience for PLWE. For example, self-advocacy is shown as a necessity that prompts their healthcare providers to listen, refer to specialists, and prevent what is known as the “medical merry-go-round” (Cox et al., 2003). Beyond medical care, PLWE have been shown to use multiple coping strategies to manage the condition, including yoga, nutrition, psychotherapy, mindfulness meditation, and

increased reliance on complementary and alternative medicine (CAM) (Adamietz et al., 2021; Evans et al., 2022).

1.6 Sleep-Related Healthcare Journeys in Endometriosis

The consensus among many researchers on PLWE is that sleep disturbances require routine evaluation in healthcare settings and a personalised care approach (Facchin et al., 2021; Leone Roberti Maggiore et al., 2017; Nunes et al., 2015). Many of these studies also conclude with statements highlighting the importance of recognising, researching and paying attention to sleep health in endometriosis, and that importance should be placed on sleep-related interventions for PLWE for the sake of patient well-being (Chaichian et al., 2024; Davie et al., 2020; Ramin-Wright et al., 2018; Sumbodo et al., 2024). However, despite this, very little research has yet explored the healthcare and management strategies for sleep disturbances in PLWE.

Few small qualitative studies examined how PLWE manage fatigue (Cole et al., 2021; Grogan et al., 2018; Sinclair et al., 2020). These studies find that some PLWE avoid social events to conserve energy or refrain from taking pain medications to stay alert during the day, while others engage in 'self-care' practices such as resting, using heat-packs, meditation, or cannabis products to help fall asleep (Armour et al., 2019; Evans et al., 2022). However, these findings are all secondary, and the research was not specifically dedicated to sleep disturbances.

To the best of my knowledge, only one small South African study has directly explored sleep-related management strategies used among PLWE (Sibande & Roomaney, 2022). Sibande and Roomaney (2022) interviewed 25 PLWE about their sleep and sleep management strategies. The primary finding was that the strategies commonly used were very personalised and planned. Many pace themselves to preserve energy, and many use supplements, rest, and energy drinks to cope. This study ultimately suggested that no interventions for endometriosis-related fatigue exist.

Beyond this research, no other studies to date have examined the healthcare journeys or management strategies for sleep disturbances in PLWE. In an AoNZ context, the gap is even more pronounced, as no research exploring sleep or sleep-related

health care decisions and experiences has yet been conducted among people living with endometriosis.

1.7 Research Gap and Study Aims

Altogether, the existing literature has established that sleep disturbances are highly prevalent among PLWE and pose a significant threat to health and well-being. This body of literature has also demonstrated multiple ways in which sleep disturbances are linked to endometriosis, both physiologically and psychologically. Despite this, few studies have explored how this population manage their sleep disturbances. Much of the existing research relates to pain, while sleep disturbances remain relatively overlooked.

Internationally, the understanding of how this population seek support for their sleep-related difficulties, including what care they receive, what decisions they make and how they experience sleep care, remains limited. In AoNZ, this gap is particularly pronounced, as no research has yet demonstrated the sleep-related healthcare decisions or experiences in PLWE. Accordingly, this study seeks to examine one of the established yet currently overlooked aspects of endometriosis—sleep disturbances. As such, the objectives of this study are to (1) evaluate the current sleep of PLWE in AoNZ, (2) explore the sleep-related health decisions of PLWE in AoNZ, and (3) explore the lived experiences of sleep-related healthcare journeys in PLWE in AoNZ. In doing so, this study addresses a gap in the literature by asking, “What are the sleep and sleep-related healthcare decisions and experiences among people living with endometriosis in Aotearoa New Zealand?”.

Chapter Two: Methodology

This section outlines the methodological approach and procedures used in this research on the sleep and sleep-related healthcare decisions and experiences among people living with endometriosis (PLWE) in Aotearoa New Zealand (AoNZ). First, the theoretical perspective of this study is explained, followed by a researcher's positionality statement. Next, the study design—including details of the development process—is presented. Finally, the ethical considerations and the analysis method of this study are outlined.

2.1 Theoretical Perspective

This thesis research takes a critical realist ontological and epistemological framework, which assumes that reality exists independently of human experience, while recognising that knowledge of this reality is partial and shaped by contextual influences (Fletcher, 2016; Maxwell, 2012). From this perspective, endometriosis, sleep disturbances and related healthcare experiences are understood as real, embodied phenomena with material consequences, even when they are not recognised, observed or understood.

Within the context of this study, critical realism acknowledges that sleep disturbances in endometriosis may be shaped via biological mechanisms, while recognising that these mechanisms are only ever partially accessible through research. Pain and sleep disturbances can therefore exist regardless of medical recognition or diagnostic confirmation. Experiences of sleep and sleep-related healthcare decisions in PLWE are shaped by interacting biological, social, psychological, cultural, gendered and systemic factors (Bhaskar & Hartwig, 2016; Crotty, 2020). Participants' accounts are treated as situated interpretations of real experiences, situated within a broader social and healthcare context.

A feminist critical health perspective further informs this positioning. This recognises the historical marginalisation and structural inequities of women's health concerns and challenges the androcentric, reductionist framings of health (Hesse-Biber, 2014). Together, these perspectives view sleep disturbances and sleep-related

healthcare journeys in PLWE as both embodied and socially situated phenomena, which reflects a nuanced, layered, feminist understanding of experience (Hesse-Biber, 2014; Lupton, 2012).

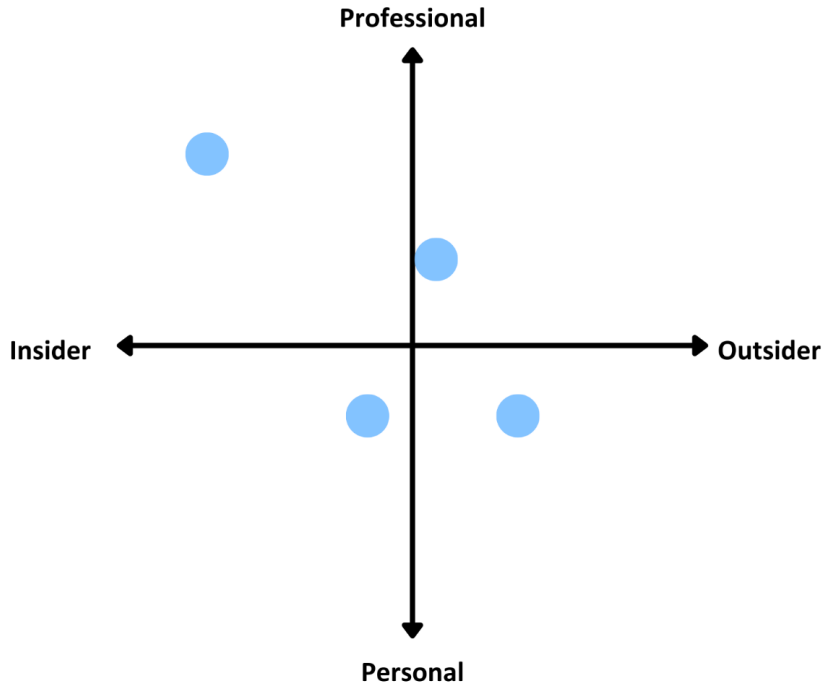
2.2 Reflexivity and Positionality Statement

Reflexivity is an ongoing process of critical thinking, self-analysis, and self-disclosure that allows the researcher to question how they are influencing the knowledge being created, which requires examination of the implications, limitations and opportunities that arise from the research approach (Finlay, 2002). Throughout the research design and analysis, I engaged in reflexivity by acknowledging my biases and subjectivities that exist in the production of knowledge (Jamieson et al., 2023; Lazard & McAvoy, 2020).

As I engaged in research from a feminist and critical health perspective, binary framings like insider-outsider positionality are rejected, and instead, relational knowledge makes positionality exist on a continuum rather than a fixed state (Gair, 2012; Hesse-Biber, 2014). As such, I have plotted multiple points on a graph to help conceptualise and reflect on my multiple, situated, relational, and contextual positionalities in this research. Figure 2.1 demonstrates four points of my positionality to this research topic, which is then followed by a reflection on how these positions may influence the study design process.

Figure 2.1

Researcher Positionality on the Research Topic



Like many researchers, I am partly motivated to explore this topic based on my own experiences. For context, I am a menstruating, cisgendered, middle-class Pākehā woman who has personally experienced challenges navigating the medical system in relation to my reproductive health. Although I do not have a diagnosis of endometriosis, I have had polycystic ovary syndrome – a hormonal condition similarly characterised by chronic symptoms, limited treatment options, and experiences of medical dismissal. My own experiences with living with gynaecological health issues, and in navigating healthcare for these confusing symptoms, have ultimately led me to an interest in how others experience and manage their health and well-being.

My professional background is in naturopathic and herbal medicine support for fertility-related issues, and in support and advocacy work for Insight Endometriosis- a charity that supports and advocates for those navigating the challenges and treatment decisions associated with living with endometriosis. In these lines of professional work,

I have regularly engaged with PLWE and listened to many health journeys and experiences associated with the condition over the past five years. Through these professional experiences, I have developed a deep passion for supporting the well-being of those with chronic illness, which has led me to pursue post-graduate studies in psychology.

I acknowledge that both my professional and personal experiences have positioned me as both a partial 'insider' and, simultaneously, an 'outsider' within this research context, where my degree of closeness to the phenomena and experiences being studied is both near and slightly far away. These dual perspectives have, in part, shaped how I perceive women's healthcare experiences and endometriosis, more generally.

My 'outsider' perspective on the research is that of someone without sleep disturbances or endometriosis, which provides a crucial distance from which to approach the data critically. It also allows me to capture the taken-for-granted perspectives on the subject without getting attached or over-identifying. Additionally, my professional immersion with the community gives me relational and empathetic 'insider' knowledge, while my personal experiences make me proximate to the participants' experiences and journeys. This is beneficial in this research context as I have deep empathy for the participant group and am sensitive to some of the complexities and challenges that may be frequently faced (Gair, 2012).

Simultaneously, I recognise that this "insider" perspective has its limitations, such as difficulty recognising patterns in data analysis due to familiarity with the community (Chavez, 2008). Therefore, I use critical reflexivity to understand how my positionality is shaped by intersectional factors of my personal and professional experiences (Crenshaw, 1991). For example, the PLWE with whom I come in contact through my naturopathic work are often of a higher socioeconomic background, predominantly Pākehā, may have had negative experiences with public healthcare, and have usually already engaged in holistic health frameworks – often sharing a similar positionality to my own. Those who seek advocacy and support via Insight Endometriosis are frequently dissatisfied with conventional care, too. Given my exposure, professional experiences introduce a perspectival bias in my understanding

of PLWE with sleep concerns – one that may overrepresent the voices of health-literate, mostly Pākehā people, who have access to private healthcare, for example, and who may be dissatisfied with conventional management options available through public healthcare.

Additionally, as a complementary and alternative medicine (CAM) practitioner, I am aware that I hold a professional and emotional investment in the perceived efficacy and experiences of CAM therapies. Therefore, I must be aware that I cannot assume that journeys and experiences will be similar to mine or those of people I have worked with to avoid presumption of sameness (Lazard & McAvoy, 2020). Further to this, I am a post-graduate psychology student who is seeking a professional career in health-related psychology. I am aware that I also hold an emotional investment in the perceived efficacy and experiences of psychological therapies for sleep in PLWE.

Holding both insider and outside perspectives provided a unique strength to this research because it enabled me to design a study with awareness of the nuanced challenges faced, while simultaneously retaining analytical distance (Corbin Dwyer & Buckle, 2009; Hayfield & Huxley, 2015; Jamieson et al., 2023).

2.3 Study Design

The study aimed to explore current sleep health, sleep-related healthcare decisions, and experiences of PLWE in AoNZ. In alignment with these aims, the study was designed to capture an overview of sleep disturbances and sleep-related health care patterns among participants, while also exploring the context and lived experiences that shape how these realities are understood.

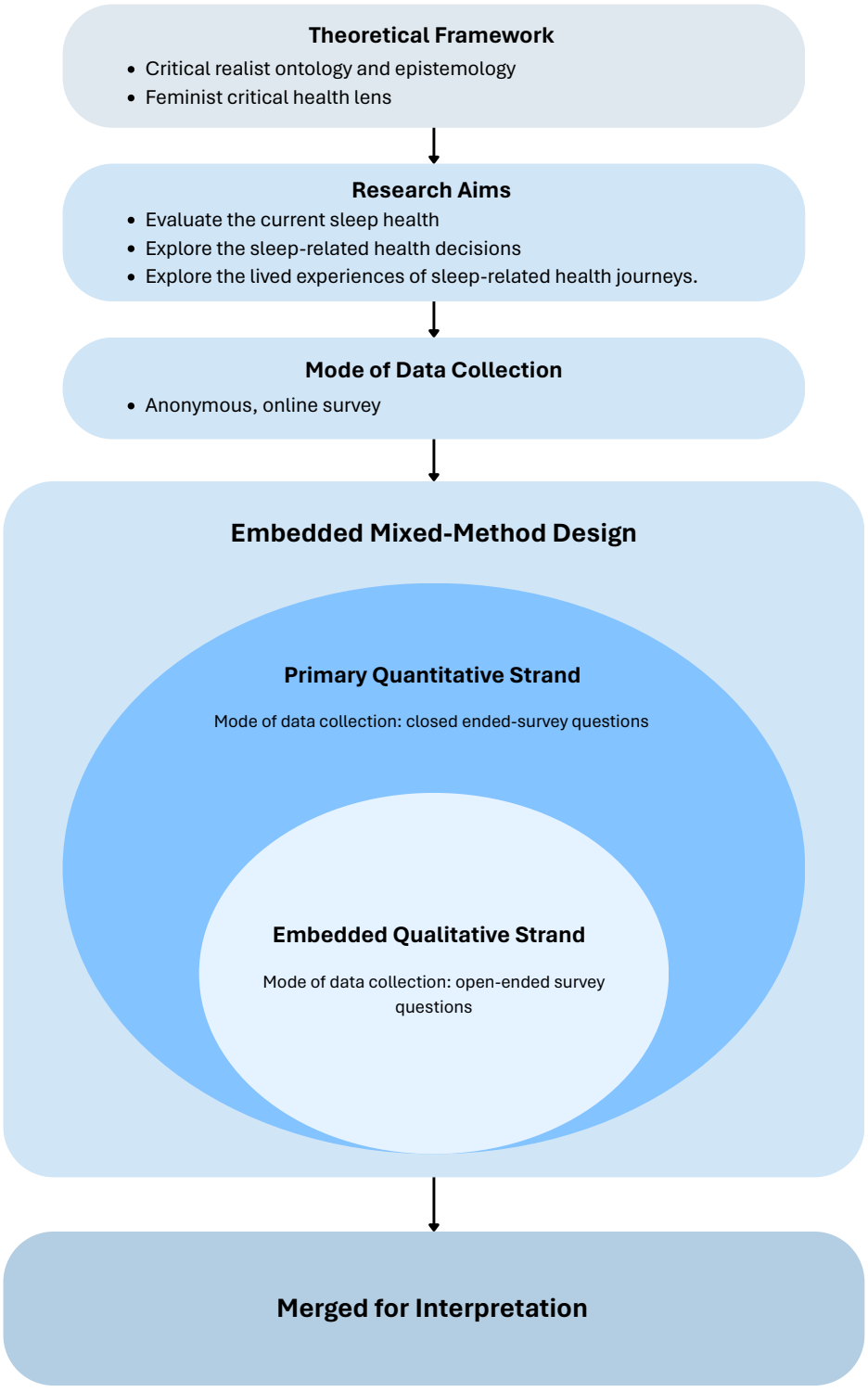
As discussed in Chapter 1, only one qualitative study has examined fatigue-management strategies among PLWE to date, conducted in South Africa (Sibande & Roomaney, 2022). No published research has yet explored sleep-related management and experiences of PLWE, in an AoNZ context. Therefore, a mixed-method design was deemed most appropriate to fulfil the exploratory research aims. This approach was chosen because it acknowledges that neither statistics nor narratives alone can fully capture the complexity of sleep and sleep-related healthcare experiences for PLWE;

instead, qualitative and quantitative methods are used together to help explain the real, embodied phenomena of sleep disturbances in this demographic (Creswell & Plano Clark, 2018; McLeod, 2024). The mixed-method approach used accommodated both the measurement of observable patterns alongside the exploration of how these patterns are experienced and interpreted within a broader social and healthcare context.

An explanatory, convergent, parallel mixed-methods design was used to address the research aims. This design included an embedded qualitative component within a predominantly quantitative design, using an anonymous online survey to collect both quantitative and qualitative data simultaneously. These two datasets were analysed separately, then merged for interpretation, in alignment with Creswell and Plano Clark (2018) framework. Figure 2.2 summarises the study design chosen for this research, including the integration of components.

Figure 2.2

Study Design: Parallel Convergent Embedded Design



Note. This was adapted by an explanatory, parallel convergent, embedded design by Creswell and Plano Clark (2018).

An anonymous online survey was selected as the most appropriate mode of data collection to show sensitivity to the context of the participants (Yardley, 2017), and to encourage inclusive participation, accessibility and psychological safety (Creswell & Plano Clark, 2018). It was considered that PLWE with sleep disturbances often experience symptoms such as fatigue and pain, which may limit their capacity to access and participate in interviews or focus groups. Additionally, the stigma, medical dismissal and emotional distress often associated with endometriosis care may make face-to-face data collection methods uncomfortable or inaccessible.

Quantitative data were collected using closed-ended survey items and validated scales, as detailed in Section 2.5.2 below. Using the quantitative data, a healthcare-seeking journey map was developed to visualise the sequential healthcare decisions made when seeking professional support for sleep challenges (described in detail in Section 2.9). Journey mapping is a visually interpretive method of presenting a sequence and stage of care that a patient follows across different health services (Sijm-Eeken et al., 2020) and has been used to track and portray health services in other sleep and mental health-related research (Mahanjana et al., 2025; O'Regan et al., 2023; Vesinurm et al., 2025). Qualitative data were collected using open-ended question items in the survey, as detailed in Section 2.5.3. Responses were then analysed using Reflexive Thematic Analysis (described in detail in Section 2.10). These approaches are compatible with critical realist epistemology and a feminist critical health lens, which emphasises meaning-making and researcher reflexivity (Braun & Clarke, 2022; Crotty, 2020). The intention of combining open and closed questions about patient healthcare experiences was to invite new perspectives that may not yet have been considered (Semyonov-Tal & Lewin-Epstein, 2021).

The online survey was anonymous and used a convenience sample. In this preliminary research with a clinical population, a convenience sample ensured that a diverse population could be recruited.

2.4 Participants

Using a convenience sampling strategy, participants were recruited online using social media. Participants needed to match the following inclusion criteria:

1) 18 years old and older
2) Living in Aotearoa, New Zealand
3) Diagnosed with endometriosis by a clinician
4) Have not had any surgery in the past eight weeks
5) Are not currently pregnant
6) Have, or have had, sleep disturbances.

Participants under the age of 18 years were excluded from this study to avoid developmental changes in sleep and menstrual-cycle physiology that may influence symptoms. Sixty-six percent of the first symptoms of endometriosis emerging before the age of 20 (Bourdel et al., 2006). Those with a self-reported clinical diagnosis of endometriosis, rather than a laparoscopic surgical confirmation were eligible to participate, reflecting the critical realist position that embodied suffering does not depend on surgical diagnosis. This stance also supports a feminist critical health view that participants are experts of their experiences, which acknowledges self-reported diagnoses in the context where access to surgical confirmation may be delayed or inaccessible. Recent surgeries (laparoscopy or other) in the past eight weeks, and those who were pregnant were excluded due to their potential to complicate sleep and endometriosis symptom-related outcomes (Alzueta & Baker, 2023; Baker & Lee, 2018). This also ensured that sleep symptoms, complications, emotional wounds, and/or medication related to recent surgery or pregnancy were not mistaken for current sleep disturbances or related to endometriosis.

Gender was not included as an eligibility criterion, as endometriosis predominantly affects those who are assigned female at birth, including women, transgender men, and non-binary people. Excluding participants based on gender could reinforce binary assumptions and risk excluding valid experiences.

2.5 Survey Development

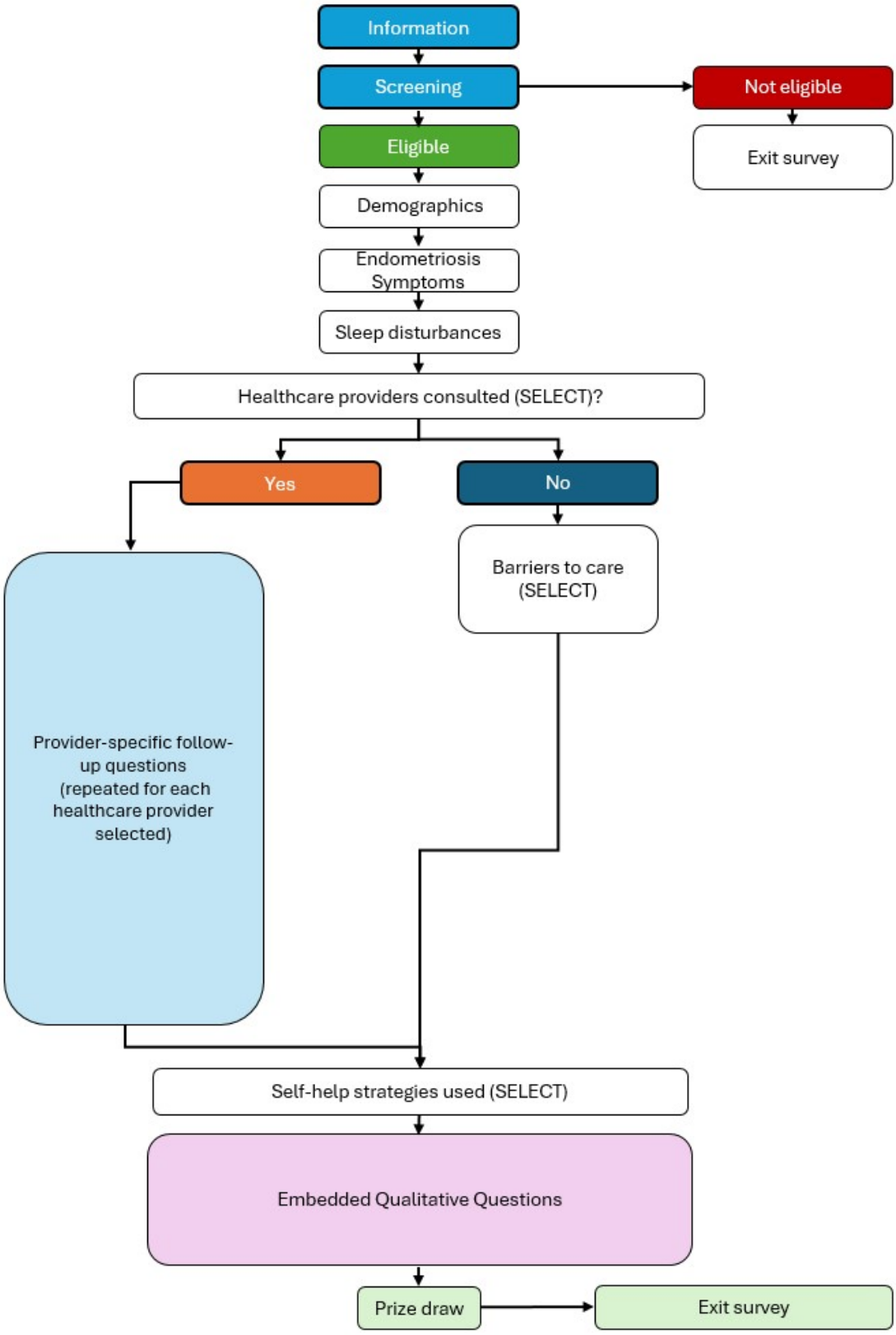
2.5.1 Survey Design and Flow

In total, 27 items were included in the online survey, grouped into seven conceptual groups: (1) demographics, (2) endometriosis symptoms, (3) sleep disturbances, (4) healthcare provider use, (5) barriers to care, (6) self-management strategies, and (7) qualitative questions. The survey was built using an online platform, Qualtrics (Provo, UT). The overall survey structure is summarised in Figure 2.3, which illustrates the sequential flow of the seven conceptual groups, including a mid-way branch, where participants were directed to different groups of questions based on whether they have discussed sleep concerns with a healthcare provider or not.

As detailed in Figure 2.3, the survey began with demographic, endometriosis and sleep-related questions. Participants were then asked if they have ever discussed their sleep concerns with a healthcare provider. Participants who had discussed their sleep concerns with a healthcare provider were directed to a sequence of questions capturing information about each healthcare provider they had consulted. Those who had not sought professional healthcare for their sleep disturbances were instead directed toward a question about what had stopped them from speaking with a healthcare provider about their sleep concerns. All participants were asked about strategies they had used to support their sleep, without the help of a healthcare provider. All participants were then invited to respond to two open-ended questions at the end of the survey. All participants who completed the survey were invited to enter a prize draw.

Figure 2.3

Flow Diagram of the Structure of Questions in this Survey



2.5.2 Survey Content and Response Format

The survey content was designed to capture a broad range of experiences using a combination of answer formats. These measures included multiple-choice and text-response questions, questions with 5-point Likert scales, and questions in which answers could be repositioned into a sequence (i.e., a particular order). It was considered that multiple-choice items with researcher-determined answers might not fully represent an individual's healthcare experiences (Semyonov-Tal & Lewin-Epstein, 2021). Therefore, to promote inclusivity and reflect a diverse range of experiences, multiple-choice items were developed based on existing literature and clinical experience, with "other" and "not applicable" options available where relevant. The wording of all survey items was carefully reviewed to avoid gendered language and medical jargon, except when quoting directly from the literature.

Tables 2.1-2.6 present the survey questions included in each of the seven groups, including the key concepts captured and the response options used. This is followed by an explanation of the qualitative questions. The full questionnaire, complete with wording, response formatting and layout used, can be found in Appendix B.

Table 2.1 presents the demographic variables captured in the survey.

Table 2.1

Demographic Variables Included in the Survey

Variable	Description
Age	Participants recorded their age, measured in years. Response options were limited to the range of 18-99 years, recorded in whole numbers.
Self-identified ethnicity	Participants could select one or more options from a list of ethnicities. Responses were measured using *New Zealand Ethnicity Data Protocols* (Ministry of Health, 2017) to align with nationally-endorsed, culturally appropriate wording. Responses were later catagorised into six groups using *Stats NZ's Ethnicity New Zealand Standard Classification 2005* "Level 1" hierarchal classification standards (Stats NZ, 2005). See Section 2.9.1 for more details.
Current reproductive stage	The reproductive stage refers to pre- and post-menopausal shifts, where fertility changes. Participants could select one option between pre-, peri-, post-menopausal, or "I'm not sure". This was captured to identify hormonal shifts that may influence the experience of endometriosis and of sleep disturbances.
Co-existing health conditions	Participants could select one or more options from a list of co-morbid conditions that are known to influence sleep and endometriosis experiences. The range of response options were drawn from the literature review in Chapter 1.

Table 2.2 presents the survey variables related to endometriosis.

Table 2.2

Endometriosis Symptom Variables and Descriptions Used in the Survey

Variable	Description
Current symptoms	Participants could select one or more options from a list of symptoms that they currently experience and that relating to endometriosis. Symptom options were informed by *Ministry of Health Guidelines for Diagnosis of Endometriosis* (Ministry of Health, 2020), and the literature review in Chapter 1.
Current symptom severity	Captured with a 5-point Likert scale ranging from "Not at all" to "Extreme".
Years since symptom onset	Participants could select one option from a list of time categories. The timeframe options from which participants could choose included a range from "less than one year ago" to "more than 30 years ago".
Current medication used	Participants could select one or more options from a list of medications that are common treatments in endometriosis. Medication options were informed by *Ministry of Health Guidelines for Diagnosis of Endometriosis* (Ministry of Health, 2020).
Health-related quality-of-life impact scale	Measured using the Endometriosis Health Profile (EHP-5) scale. The EHP-5 was used with permission from the copyright holders. The EHP-5 is © University of Oxford and was used under licence from Oxford University Innovation, all rights reserved. The EHP-5 is a five-item questionnaire which provides a measure of the endometriosis-specific impacts on quality of life. The five items in the EHP-5 assess pain, control and powerlessness, social support, emotional well-being and self-image, assessed via 5-point Likert scales ranging from "never" to "always" (Jones et al., 2004; Jones et al., 2024). This measurement has been demonstrated to be a valid and reliable short-form outcome measure among adults with endometriosis (Jones et al., 2004). It has been used in several clinical trials involving PLWE (Bourdel et al., 2019).

Take 2.3 summarises the variables that this survey captured in relation to sleep disturbances.

Table 2.3

Sleep Disturbance Variables and Descriptions used in the Survey

Variable	Description
Sleep duration per 24 hours	Participants responded by providing hours and minutes they slept in 24 hours, including naps. Responses were recorded in one-hour and one-minute increments (1-23 hours, 0-59 minutes). This question has been used in previous surveys in AoNZ (e.g., Mihaere et al., 2009; Paine et al., 2004).
Sleep disturbance severity scale	Sleep disturbances were measured using the Patient-Reported Outcome Measures Information System for Sleep Disturbance 8b short form (PROMIS-SD-8b) scale. The PROMIS-SD is a universal measure of self-reported sleep disturbance, quality, and satisfaction over the past seven days (Health Measures, 2025). The PROMIS-SD-8B is an 8-item measurement, each of which is scored on a 5-point Likert scale, which is then summed and calculated as a standardised T-score, where higher scores indicate greater sleep disturbance. The PROMIS-SD-8B has high psychometric properties and has been used widely in adult populations (Cella et al., 2010). It captures subjective difficulties of falling and staying asleep, sleep satisfaction, perceived sleep quality and continuity, which covered several dimensions of the modern definition of sleep health (Buysse, 2014; St-Onge et al., 2025).
Years since sleep disturbance onset	Participants could select one option from a list of time frame categories. The options ranged from “less than one year ago” to “more than 30 years ago”.

Descriptions of variables relating to healthcare provider use captured in this survey are summarised in Table 2.4.

Table 2.4

Healthcare Provider Variables and Descriptions

Variable	Description
History of healthcare provider consulted	Participants reported on whether they had ever discussed their sleep concerns with a healthcare provider. Participants could respond by answering either “yes” or “no”.
Which healthcare providers were consulted	Participants could select one or more options from a list of healthcare providers commonly consulted for both sleep concerns and for endometriosis. The list of healthcare providers was informed by the literature review in Chapter 1, and by *Ministry of Health Guidelines for Diagnosis of Endometriosis* (Ministry of Health, 2020).
Chronological order of healthcare providers consulted	Participants responded by reporting the chronological ordering in which they had consulted the providers that they had selected in the previous question. Participants did this by selecting and dragging each option into an order which reflected their order of access.
Years since first consultation, per healthcare provider consulted	For each healthcare provider that participants consulted (determined by answers to previous questions), participants could select one of the options from a list consisting of various time frames. These time frames ranged from “less than one year ago” to “more than 10 years ago”, including an option for “I don’t remember”.
Total number of visits, per provider consulted	For each healthcare provider consulted, participants could select one of the options from a list consisting of various time frames ranging from “1” to “more than 10”, including an option for “I don’t remember”.
Comfort level, per provider consulted	For each healthcare provider consulted, participants could select one option from a 5-point Likert scale ranging from “extremely uncomfortable” to “extremely comfortable”. Responses were captured to explore the emotional aspects of healthcare, such as trust, that can impact the care experience in PLWE (Mikesell & Bontempo, 2023).

Variable	Description
Support provided with, per provider consulted	For each healthcare provider consulted, participants could select one or more options from a list of common treatments relating to sleep care, including an option which read "I was not given any support". Medical treatment options were informed by strategies outlined in *Diagnosis and Management of Endometriosis in New Zealand* for primary, secondary and tertiary care providers (Ministry of Health, 2020), and by the literature (e.g., Adamietz et al., 2021; Edinger et al., 2021; Sateia et al., 2017).
Efficacy of support provided with, per provider consulted	For each healthcare provider consulted, participants could select one option from a 5-point Likert scale ranging from "not effective at all" to "extremely effective". This was included to quantify perceived benefit of healthcare.
Satisfaction of care, per provider consulted	For each healthcare provider consulted, participants could select one option from a 5-point Likert scale (ranging from "extremely dissatisfied" to "extremely satisfied"). This question captured respondents' evaluation of healthcare relative to their expectations. Patient satisfaction was chosen because it reflects aspects of healthcare quality, such as responsiveness, communication between patient and health provider, not simply clinical outcomes (Batbaatar et al., 2017). This question was included to detect patterns in satisfaction across healthcare providers consulted, to discuss in relation to global and AoNZ dissatisfaction trends observed in healthcare settings for PLWE (Cunnington et al., 2024; Ellis et al., 2022).

Table 2.5 includes a description of the variable used in the survey to capture reasons for why participants did not seek professional healthcare for their sleep disturbances.

Table 2.5

Barriers to Care Variables and Descriptions Captured in the Survey

Variable	Description
Perceived barriers to health-seeking decisions	Participants were asked to select one or more options from a list. The list provided options including common barriers to healthcare, as informed by previous endometriosis and sleep literature (e.g. Evans et al., 2022; Manocchia & Ware, 2001; Seear, 2009a).

Variables used to capture the self-management strategies in the survey are described in Table 2.6.

Table 2.6

Self-management Behavioural Variables and Descriptions Captured in the Survey

Variable	Description
Strategies used to support sleep, without the input of a healthcare provider	Participants could select one or more options from a list of self-management strategies commonly used for sleep disturbances. The list of options were informed by self-management strategies that were identified in the limited endometriosis-related literature (Sibande & Roomaney, 2022; Sinclair et al., 2020) and that were identified in the literature review in Chapter 1 (e.g., O'Regan et al., 2023).
Perceived efficacy of strategies used	Participants reported on their perceived effectiveness of the strategies that they had used. Participants could select one option from a 5-point Likert scale ranging from “strongly disagree” to “strongly agree”.

2.5.3 Qualitative questions

The two open-ended, qualitative questions were included at the end of the survey, which invited participants to share their reflections on their sleep-related health-seeking experiences. These included:

1) “If there was one thing you wished could be different about your healthcare experience for sleep, what would it be?”
2) “Is there anything else you’d like to share about your experience seeking help for sleep?”

The questions were deliberately broad and non-directive to invite insights that participants felt were important, and that may not have been captured by the closed-ended questions. The open-ended questions were placed at the end of the survey as they were deemed less confronting, and allowed participants to reflect on the questions that had been answered prior (Braun & Clarke, 2022). The intention was also for these questions to elicit responses that could reflect the healthcare expectations and values held by participants (Larson et al., 2019). Both qualitative questions were optional to answer.

2.5.4 Reflexive Statement about the Qualitative Question Development

During the development of the qualitative questions, I recognised that their wording may stem from my preconceptions about healthcare experiences. To mitigate potential bias, I acknowledged this perspective and reviewed the questions in close collaboration with three academic supervisors from two different schools and with different research and academic backgrounds.

2.6 Ethical Considerations

This research was assessed through the Massey University research ethics process and deemed to be ‘low risk’. As a ‘low risk’ project, it was not subject to a formal ethical review process from the Massey University Human Ethics Committee. Instead, it underwent peer review, and a Low-Risk Notification was completed (see Appendix C).

Ethical considerations followed the principles of *Massey University’s Code of Ethical Conduct for Research, Teaching and Evaluation Involving Human Participants,* and were informed by feminist values of inclusivity, accessibility, empowerment and representation (Hesse-Biber, 2014). The considerations discussed during the peer-

review process included how this study design and procedures planned to uphold participants anonymity, confidentiality, autonomy, and maintain sensitivity toward participants personal data. The storage and management of data, and what was planned to minimise participant burden research process were also discussed.

No identifying information was collected from participants in the survey. It was anonymous in support of maintaining sensitivity toward personal data, and in support of participants feelings of comfort while sharing their experiences. Confidentiality was maintained when collecting details for the optional prize draw by ensuring they were collected via a separate, unlinked Qualtrics survey and permanently deleted after the draw.

In support of participant autonomy, the information sheet and survey questions (Appendix B) was written in plain, non-medical language. The information sheet also informed participants of their ability to skip any questions, or exit the survey at any time, in support of providing informed consent. The survey was designed to ensure participants were presented only with relevant questions and reduced response burden by avoiding irrelevant questions and qualitative questions were made optional in efforts to minimise participants' burden. Further, website links to educational and support resources were provided in the information sheet and at survey completion to promote well-being.

Secure data storage was maintained when storing participants data by ensuring anonymous data were stored securely at the Sleep/Wake Research Centre on a username-access-limited server hosted by Massey University, to be retained for ten years. Cultural responsibility was guided by the principles of the *Te Ara Tika Guidelines* and the ethical framework of *Te Tiriti o Waitangi*, promoting equity, respect, and partnership throughout the research process.

2.7 Data Collection

In alignment with the convenience sampling method, the survey was advertised through targeted online advertising to reach people diagnosed with endometriosis who had experienced sleep disturbances (see Appendix A for the advertisement poster). The

advertisement post was disseminated online via advertising platforms of related professional networks, community groups, and on social media. These organisations and groups were also invited to share the advertisement. See Appendix D for more details on the advertising strategy, including the invitation to share the survey.
Those interested in participating were directed to an online information sheet and, if eligible, began the online survey (see Appendix B). The survey was open from 23 July to 4 August 2025, during which time a total of 490 responses were recorded.

2.7.1 Reflexive Statement about the Data Collection Process

In advertising the survey, I concealed my affiliation with the study due to my professional background. This meant that I avoided advertising this research on my professional web pages to avoid biasing the sample, as it was presumed that doing so might attract participants who may be inclined to self-manage or seek complementary and alternative medicine (CAM) practitioners, or who might feel they should participate, which might have skewed the data. For example, people who have worked with me as their naturopath may have felt obligated to complete the survey because of their professional relationship with me.

2.8 Data Management and Analysis

Two approaches were used for data analysis: quantitative statistical analysis and reflexive Thematic Analysis (TA).

2.8.1 Quantitative Data Management and Analysis

Data analysis was conducted using IBM Statistical Program for Social Sciences (SPSS; Version 30.0.0.0) (Marshall & Jonker, 2010). Quantitative data were exported and cleaned in SPSS by screening for implausible values and inconsistent responses. Most participants were automatically screened out for exclusionary responses during the survey, and all quantitative items were mandatory to advance through the questionnaire. Therefore, missing data reflected participant dropout.

Several variables were recoded and categorised to align with standardised scoring protocols. This process involved the following steps:

- Ethnicity responses were recoded into six categories using *Stats NZ's Level 1 Standard Classification,* following recommended hierarchical prioritisation protocols (Stats NZ, 2005): (1) Māori, (2) Pacific Peoples, (3) Asian, (4) Middle Eastern/Latin American/African (MELAA), (5) Other Ethnicity, and (6) European.
- The sleep disturbance severity (PROMIS-SD-8b) responses were scored and categorised according to the Health Measures (2025) manual. Raw scores were summed and transformed into T-scores (Mean = 50, SD = 10). T-scores were the categorised into several groups: normal (0-54), mild (55-59), moderate (60-69), and severe (70-100), where higher scores indicated greater sleep disturbance.
- The endometriosis-related quality of life impact scale (EHP-5) responses were scored and transformed onto a scale ranging between 0 and 100 using guidelines from the Oxford University Innovations (2025). Greater scores indicate endometriosis-related impact on quality of life.

Descriptive statistics, including means, standard errors, standard deviations, medians, ranges, and frequencies and percentages (as appropriate), were used to summarise all quantitative measures for the survey sample.

The initial descriptive summaries of sleep disturbance measures indicated variation in sleep disturbance severity within the sample. Therefore, further analyses were conducted to explore whether participants with different levels of sleep disturbance severity also differed in other characteristics of the endometriosis experience. Therefore, the continuous outcome variables were assessed for normality of distribution using Kolmogorov-Smirnov tests. All variables considered for inclusion in analyses were non-normally distributed, and non-parametric tests were used for analysis.

As a result, Kruskal-Wallis H tests were used to explore the comparison between levels of sleep disturbance severity (normal, mild, moderate, severe) and the following continuous variables:

- age
- endometriosis-related quality of life scores (EHP-5)
- sleep duration

Where Kruskal-Wallis tests indicated significance between levels of sleep disturbance, pairwise comparisons were conducted using Dunn's method with Bonferroni corrections for multiple tests. Chi-squared tests were initially considered to examine associations between categorical variables; however, these analyses were not conducted because the assumptions regarding cell counts were violated. It was not deemed appropriate to collapse multiple categories into a larger one to meet these assumptions, given the nature of the responses. A p-value < .05 was used to indicate statistical significance.

2.9 Journey Map Development

A descriptive, healthcare-seeking journey map was developed to visually portray the sequence of professional healthcare consultations along with the corresponding satisfaction and perceived effectiveness ratings. The construction of this map used data from the participants who discussed their sleep concerns with a healthcare provider (*n* = 237). Specifically, the order in which healthcare providers were consulted, drawn from responses to the question: "In what order did you see the following healthcare providers for your sleep concerns?", as well as the satisfaction and perceived efficacy ratings reported when consulting each of these providers.

To ensure clarity and interpretability, the construction of this journey map was limited to the first three levels of healthcare providers access. This was because most respondents (*n* = 177, 74.7%) reported consulting with three or fewer different providers. Additionally, only healthcare providers who were consulted by at least three participants were reported on for each level of access (i.e., were consulted first, second and third). This avoided excessive category splitting and prevented cluttering the map with very small, low-frequency categories.

2.9.1 Healthcare Providers Consulted First

To start, survey responses were analysed to determine which healthcare providers were consulted most frequently in the first instance when seeking support for their sleep difficulties (i.e., were consulted first). The two most frequently consulted providers were included individually in the map, and all other providers were classified as 'other'. These healthcare providers were labelled in the map as 'first provider consulted'.

2.9.2 Healthcare Providers Consulted Subsequently

For each healthcare provider included in the map as 'consulted first', survey responses were analysed to determine which healthcare providers were visited subsequently (i.e., were consulted second). Similarly, for each healthcare provider included in the map as 'second provider consulted', survey responses were analysed to determine which healthcare providers were visited subsequently (i.e., were consulted third). The most frequently consulted providers for those consulted second and third were included individually in the map, and all other providers with were classified as 'other'.

2.9.3 Satisfaction Scores Overlaid onto the Journey Map

The corresponding satisfaction ratings and perceived effectiveness scores were included for each healthcare provider included in the journey map. These data were drawn from responses to the questions: *"How satisfied were you with this healthcare provider?*" and "*How effective was the treatment from this healthcare provider?"*. Participants' responses for each question were scored from 1-5, where higher numbers reflected a higher level of satisfaction or perceived effectiveness. The scores drawn from participants' satisfaction responses were collapsed into three categories and colour-coded as below:

- red: Dissatisfied (scores 1-2)
- blue: Neutral (score 3)

- green: Satisfied (scores 4-5)

These scores drawn from participants' perceived effectiveness responses were similarly collapsed into three categories and colour-coded as below:

- red: Not effective (scores 1-2)
- blue: Neutral (score 3)
- green: Effective (scores 4-5)

These recoded categories were overlaid onto each healthcare provider included in the journey map.

2.10 Qualitative Data Analysis

Qualitative data were analysed using reflexive Thematic Analysis (TA) to identify patterns, meanings and themes in participants' responses. Reflexive TA moves beyond summarising qualitative data to a more interpretive and conceptual analysis which incorporates both semantic and latent meaning, themes and stories (Braun & Clarke, 2022). This method was selected for its theoretical flexibility and alignment with this study's critical realist and feminist foundations, which emphasise the lived experiences of socially marginalised groups and recognise how broader social, cultural, and gendered power structures shape those experiences.

The flexible application of reflexive TA allowed the analysis to be both inductive and deductive. Initial codes and themes were developed inductively, shaped by patterns of participants' experiences. Later, interpretation was informed deductively by theory. This hybrid approach, therefore, supported an exploration of the lived experiences of sleep-related care and the broader context in which these occur for this sample.

This process followed the six core phases of Reflexive TA: familiarisation with the data, coding, re-coding, theme development, revision and refinement (Braun & Clarke, 2022). A total of 312 participants responded to the first qualitative question, capturing what could be different about their experience to make it better, and 249 participants answered the second, which asked for further comments about their experience.

Responses were exported into Microsoft Excel for close, iterative engagement and familiarisation with the data. Coding was performed manually on a line-by-line basis, before codes were reviewed and clustered into broader categories. Then, initial themes were developed, reflecting patterns created from engaging with the data. These were reviewed, refined and visually mapped using Miro.

Reflexivity was maintained throughout the TA process. This was maintained through ongoing critical reflection and regular supervision discussions, to avoid projecting my personal hopes and needs onto participants' responses and to avoid forcing the production of knowledge that benefits the group if that is not the case in the data. The development of the qualitative components of the survey and the construction of these themes (including the stages of development, more reflections and corresponding notes) are presented in Appendix E: Reflexive TA Supplementary Material.

Chapter Three: Findings

The quantitative and qualitative findings presented in this chapter examine sleep disturbances and sleep-related healthcare decisions and experiences in people living with endometriosis (PLWE). Quantitative findings describe demographic characteristics, experiences of sleep disturbance and endometriosis, and patterns of engagement with healthcare for sleep disturbances. These are followed by qualitative findings, which present two key themes. These themes encapsulate how participants experience sleep disturbances and how their perceptions of sleep-related healthcare influence engagement with, and management of, sleep-related concerns.

3.1 Demographics

In total, 374 participants started the survey, and 312 participants completed it in full. The demographic characteristics of participants are summarised below, in Table 3.1. The sample had a wide age range (18-63 years), with participants trending to be in early adulthood than in their later years (*Mdn* = 30.5 years) (Figure 3.1). As shown in Table 1, nearly all participants reported their ethnicity, with three (0.8%) preferring not to answer. The majority identified as European (72.2%), followed by Māori (17.6%). All other self-identified ethnicities each represented less than 5% of the sample. Three-quarters (75.4%) of participants self-identified as pre-menopausal, and 9.6% were unsure of their menopausal status. Health conditions co-existing with endometriosis were highly prevalent, with most participants (88.2%) reporting having at least one. Over half (59.4%) reported having a mental health condition. Of those who included descriptions of *other* co-morbid conditions (8.8%), a range of conditions were included by a small proportion of respondents.

Table 3.1

Participants' Demographic Characteristics and Health Status

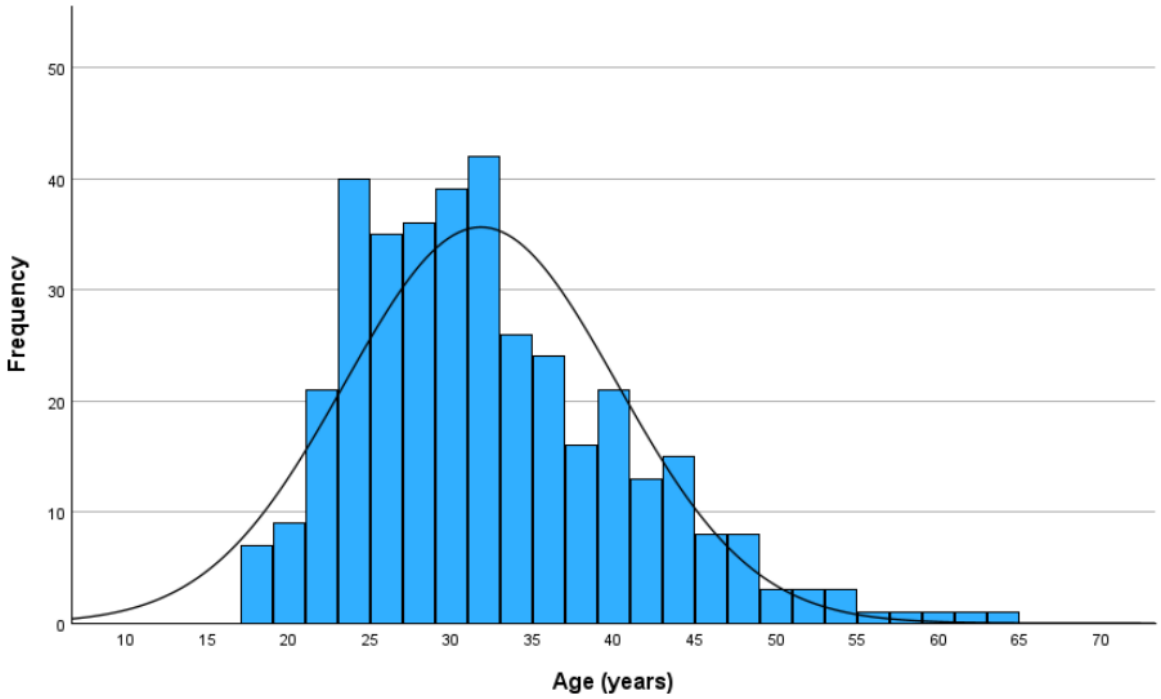
Characteristic	*n*	%	*M*	*SD*	*Mdn*	Range
Age (years)	374		31.8	8.4	30.5	18-63
Ethnicity (prioritised)						
Māori	66	17.6				
Pacific Peoples	5	1.3				
Asian	10	2.7				
MELAA [a]	16	4.3				
Other	4	1.1				
European	270	72.2				
Prefer not to answer	3	0.8				
Reproductive Stage						
Pre-menopausal	282	75.4				
Peri-menopausal	36	9.6				
Post-menopausal	18	4.8				
Not Sure	36	9.6				
Co-existing conditions [b]						
Sleep conditions	141	37.7				
Mental health condition/s	222	59.4				
Other hormone condition/s	106	28.3				
Other chronic pain condition/s	146	39.0				
Neurological condition/s	30	8.0				
Heart condition/s	22	5.9				
Metabolic condition/s	19	5.1				
Neurodevelopmental conditions	75	20.1				
Gastrointestinal conditions	141	37.7				
Other	33	8.8				
None	44	11.8				

Note. [a] Middle Eastern, Latin American, and African.

[b] Participants could endorse more than one co-existing condition.

Figure 3.1

Distribution of Participants' Age in Years



3.2 Endometriosis Characteristics

3.2.1 Participants' Endometriosis Characteristics

As summarised in Table 3.2, most of the sample (96.8%) reported currently experiencing multiple endometriosis symptoms from the list provided in the survey. Cyclical digestive issues (85.8%) and pelvic pain (85.6%) were the most frequently reported symptoms, followed by painful periods (71.1%). Most participants rated their endometriosis symptoms as moderate to extreme in severity (85%), and only one (0.3%) reported them as being not at all severe. Approximately two-thirds of participants (n = 241, 64.4%) reported currently using one or more medications to manage their endometriosis-related symptoms. The most frequently reported medications used were analgesics (pain relief or strong pain relief; 87.5%), and hormonal contraceptives (43.6%).

Table 3.2

Participants' Endometriosis Characteristics

Variable	n	%
Current endometriosis symptoms (*n* = 374)		
Painful periods	266	71.1
Pelvic pain	320	85.6
Irregular menstrual cycles	165	44.1
Heavy periods	185	49.2
Mood swings related to periods	246	65.8
Digestive issues related to periods	321	85.8
Other	78	20.9
None	12	3.2
Endometriosis severity (*n* = 358)		
Not at all	1	0.3
Slightly	39	10.4
Moderately	152	40.6
Very	121	32.4
Extreme	45	12.0
Current endometriosis-related medications (*n* = 369)		
Pain relief	199	53.9
Strong pain relief	124	33.6
Hormonal contraception	161	43.6
Antidepressant	94	25.4
Other	50	13.6

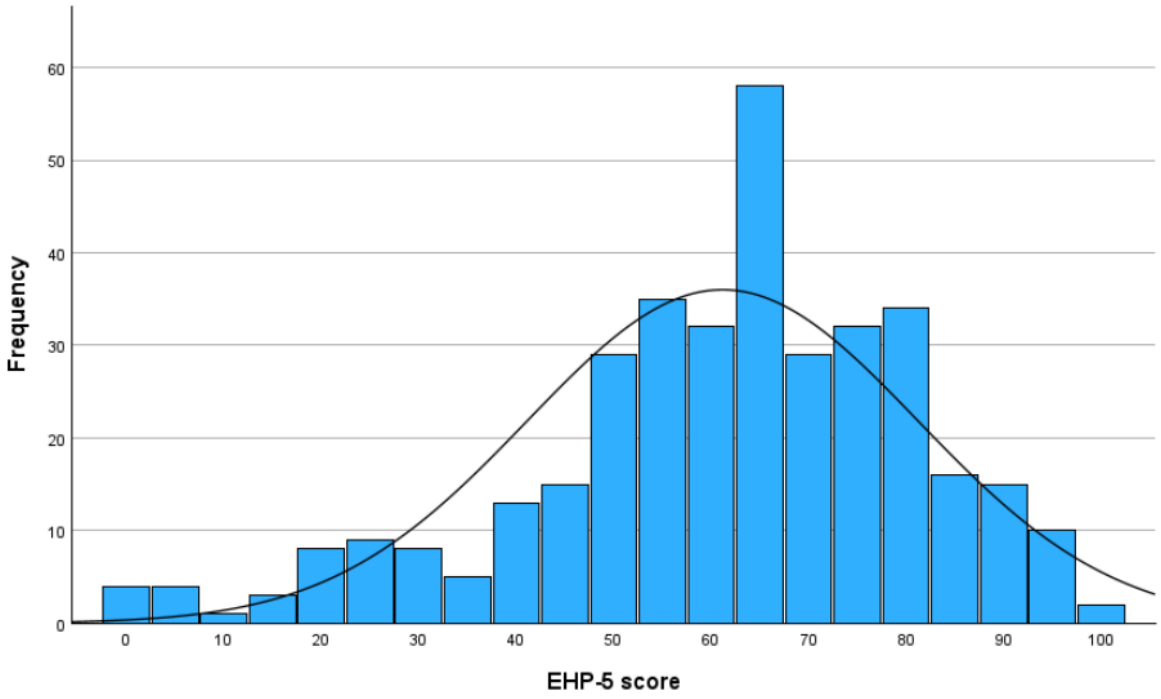
Note. Participants could endorse more than one endometriosis symptom, and medication type.

3.2.2 Participants' Endometriosis-Related Quality-Of-Life Impact

Figure 3.2 displays the distribution of participants' endometriosis-related quality-of-life scores (EHP-5). The scale ranges from 0-100, where greater scores represent higher impairment. Participants' results were distributed across the full range of the scale, with a median of 65.0. The majority of participants (*n* = 263, 72.7%) scored above the midpoint of 50.0.

Figure 3.2

Distribution of Endometriosis-Related Quality-of-Life Impact (EHP-5) Scores



Note. Higher EHP-5 scores indicate greater endometriosis-related quality-of-life impairment.

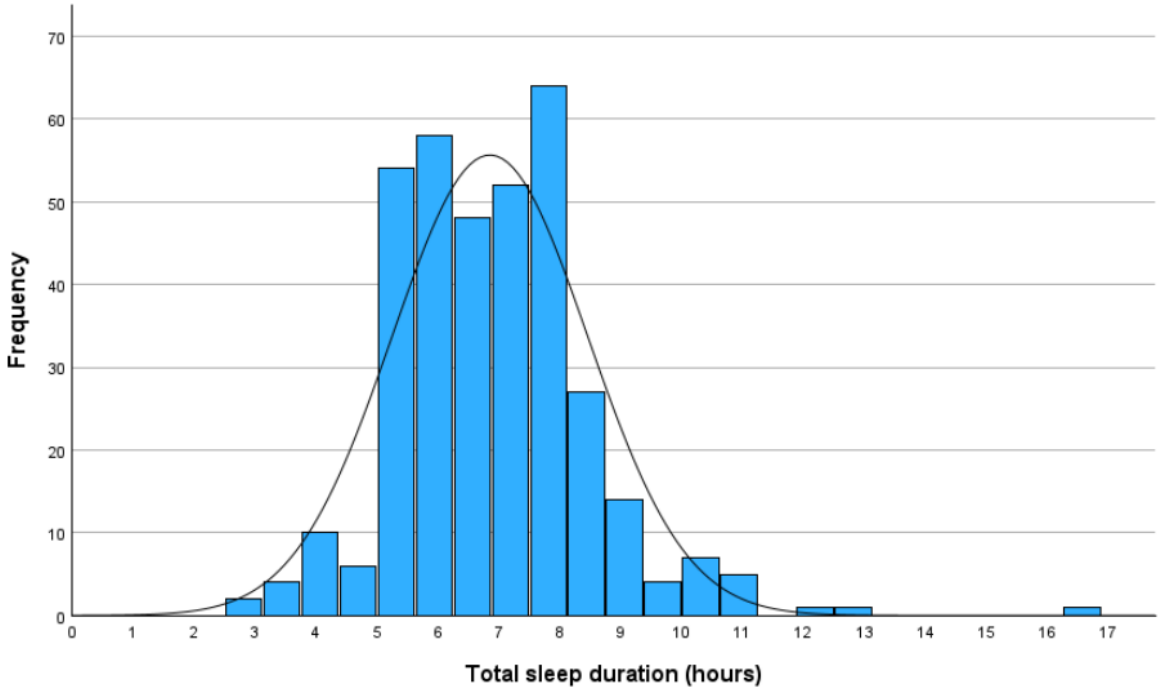
3.3 Sleep Disturbance Characteristics

3.3.1 Participants' sleep duration

Figure 3.3 shows the distribution of self-reported sleep duration per 24-hour period. Sleep durations varied among respondents, ranging from 2.5 to 16.5 hours (*Mdn* = 6.7). The distribution is non-normally distributed and have a positive skew, with a small number of participants self-reporting substantially longer duration compared to the median.

Figure 3.3

Distribution of Total Sleep Duration by Hours



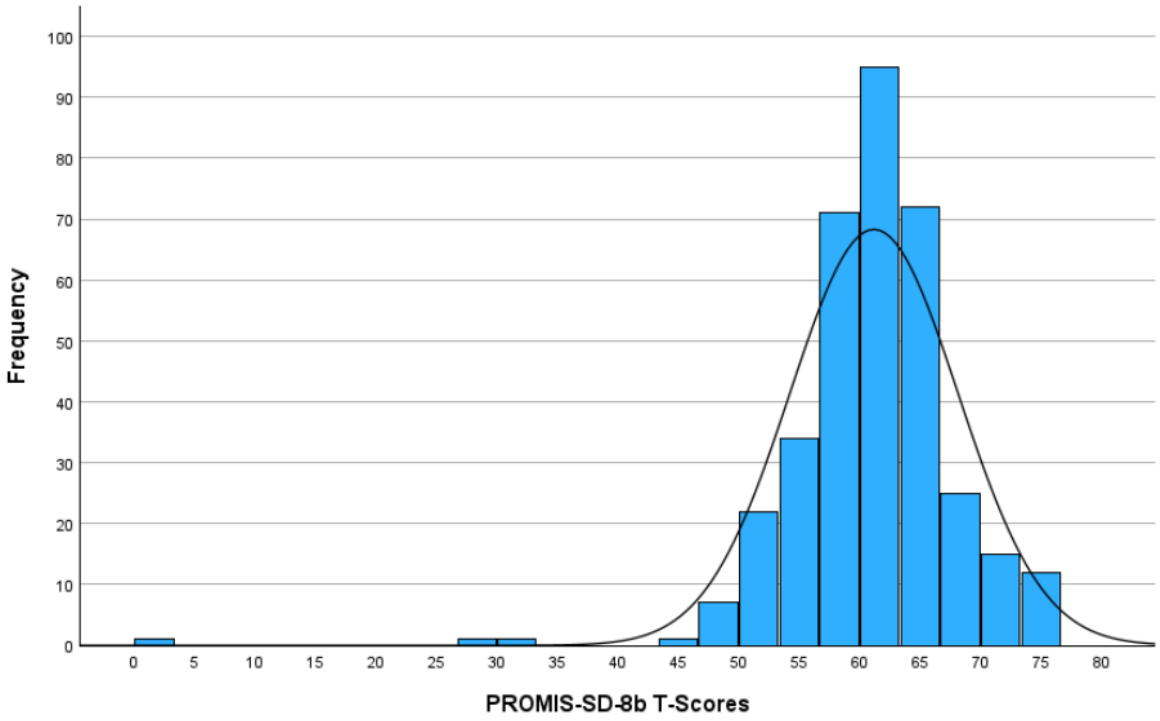
3.3.2 Participants' Sleep Disturbance Severity

Figure 3.4 shows participants' sleep disturbance severity (PROMIS-SD-8b T-scores). The PROMIS-SD-8b scores showed a non-normal distribution, with most participants scoring at the higher end of the scale. Scores ranged widely between participants (2.8-76.5), with a median of 61.5.

Participants were categorised as having normal (T-scores 0-54), mild (T-scores 55-59), moderate (T-scores 60-69), and severe (T-scores 70-100) sleep disturbance based on their PROMIS-SD-8b T-scores, which are normed against the Unites States population (mean = 50.0, *SD* = 10.0). The majority of participants (*n* = 314, 88.0%) had T-scores within the mild, moderate, or severe sleep disturbance ranges. The largest proportion of T-scores fell in the moderate sleep disturbance range (*n* = 192, 53.8%), followed by mild sleep disturbance range (*n* = 95, 26.6%), then the severe sleep disturbance range (*n* = 27, 7.6%). Few participants (*n* = 43; 12.0%) had scores in the normal range.

Figure 3.4

Distribution of Sleep Disturbance Severity by PROMIS-SD-8b T-scores



Note. Greater T-scores indicate greater severity of sleep disturbance, categorised as normal (T-scores 0-54), mild (T-scores 55-59), moderate (T-scores 60-69), and severe (T-scores 70-100).

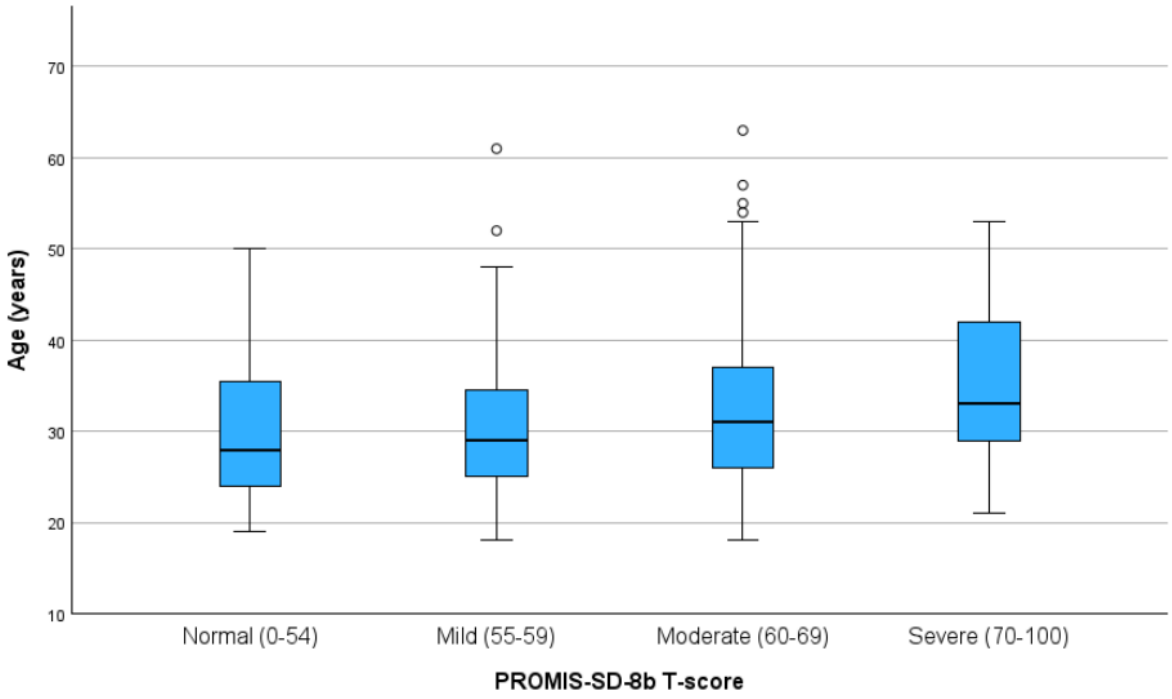
3.4 Relationships Between Key Demographic and Clinical Variables

3.4.1 Relationship Between Age and Sleep Disturbance Severity

As shown in Figure 3.5, median age was similar across sleep disturbance severity categories (normal = 28 years, mild = 29 years, moderate = 31 years, severe = 33 years). No significant difference in age was found between these categories ($H(3) = 6.990$, $p = .072$), suggesting no relationship between age and sleep disturbance severity.

Figure 3.5

Age in Years by Sleep Disturbance Severity

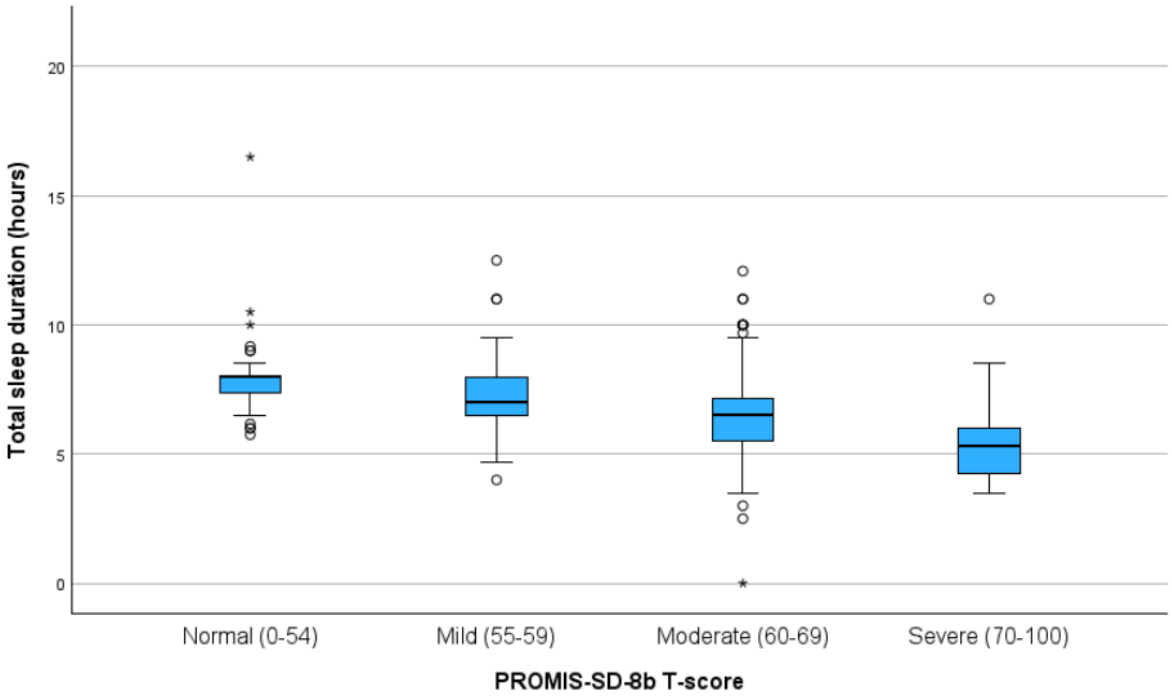


3.4.2 Relationship Between Sleep Duration and Sleep Disturbance Severity

Figure 3.6 shows the relationship between participants' sleep duration and sleep disturbance severity. A Kruskal-Wallis H Test found a significant difference in hours slept between groups of sleep disturbance severity ($H(3) = 69.833$, $p < .001$). As shown in Figure 3.6, median hours slept decreased with higher sleep disturbance scores, suggesting that a worsening in sleep disturbance severity was associated with fewer hours slept. Post-hoc pairwise comparisons showed significant differences in sleep duration compared to nearly all PROMIS-SD-8b sleep severity groups ($p < 0.05$), except for between the 'normal' and 'mild' categories.

Figure 3.6

Sleep Duration by Sleep Disturbance Severity

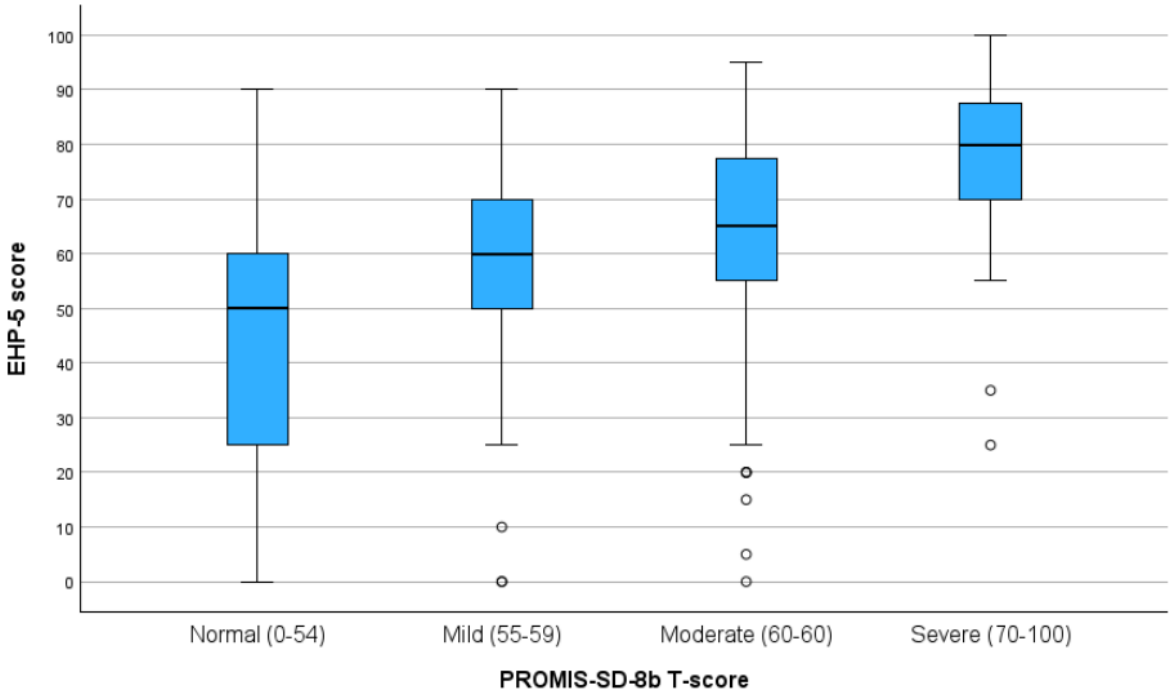


3.4.3 Relationship Between Endometriosis-Related Quality of Life Impact and Sleep Disturbance Severity

A Kruskal-Wallis H Test was used to assess whether endometriosis-related quality of life (EHP-5) scores differed between the categories of sleep disturbance severity (normal = T-scores 0-54, mild = T-scores 55-59, moderate = T-scores 60-69, severe = T-scores 70-100). A statistically significant difference was found between categories, $H(3) = 48.061$, $p < .001$. As shown in Figure 3.7, median EHP-5 scores increased with higher sleep disturbance scores, suggesting a worsening quality of life impact with increasing sleep disturbances. Post-hoc pairwise comparisons showed significant differences ($p < .05$) in EHP-5 scores between all sleep disturbance groups except between the 'normal' and 'mild' categories.

Figure 3.7

Endometriosis-Related Quality of Life Impact by Sleep Disturbance Severity



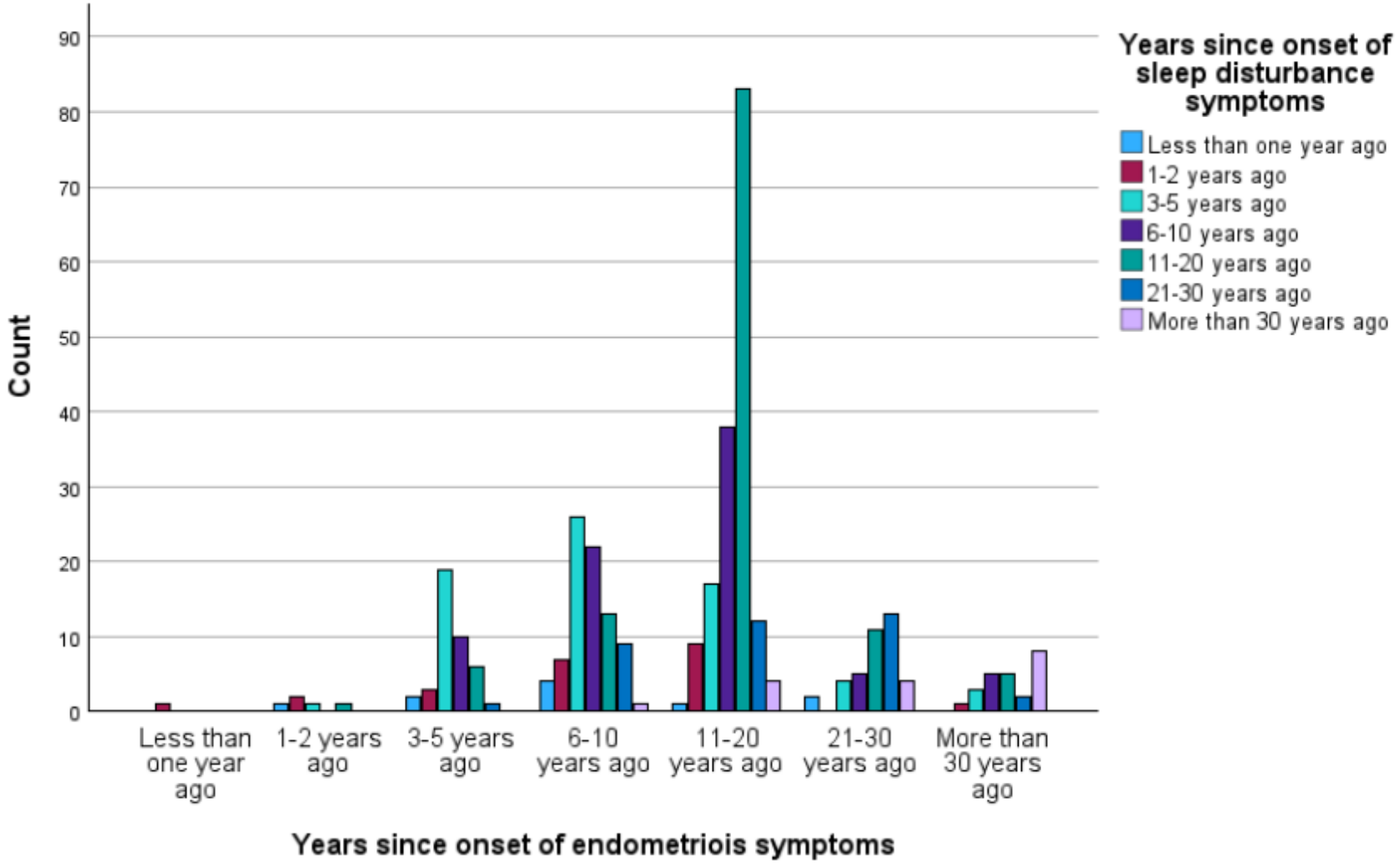
Note. This graph shows sleep disturbance severity categories according to PROMIS-SD 8b T-scores, including normal (T-scores 0-54), mild (T-scores 55-59), moderate (T-scores 60-69), and severe (T-scores 70-100). Increasing EHP-5 scores indicate a greater degree of impact on quality of life (0-100).

3.4.4 Relationship Between Years Since the Onset of Sleep Disturbances and the Onset of Endometriosis Symptoms

Figure 3.8 illustrates the relationship between the participants' onset of endometriosis and onset of sleep disturbances. Responses are clustered at similar onset periods for both variables, with the highest proportion occurring in the 11–20 years ago category (33.4% for onset of sleep disturbances; 45.7% for onset of endometriosis symptoms). Reports of more recent onset (within the past two years) were less common (9.3% for sleep disturbances; 1.9% for endometriosis symptoms), as were reports of onset more than 30 years ago (4.8% and 6.7%, respectively). More than 60% of participants (n = 236, 63.1%) reported endometriosis symptoms beginning more than 10 years ago. Similarly, nearly half (n = 173, 48.6%) reported sleep disturbance onset more than 10 years ago.

Figure 3.8

Years Since Onset of Endometriosis Symptoms by Years Since Onset of Sleep Disturbances



3.5 Sleep-Related Healthcare-Seeking and Self-Management Decisions

Participants were asked to report on their sleep-related healthcare decisions and experiences, including whether they had sought care from a healthcare professional, their experiences with each healthcare provider, and any self-help strategies they had used. Based on answers to the survey question "Have you ever discussed your sleep concerns with a healthcare provider?", the participants were divided into two groups: those who sought professional healthcare and those who did not (as discussed in Chapter 2, Figure 2.3). The following subsections present findings for each of these groups, beginning with participants who sought professional healthcare. This is then followed by the presentation of findings on self-management strategies reported by all participants, described by each respective group.

3.6 Participants Who Sought Professional Healthcare

3.6.1 Number of Healthcare providers consulted for sleep disturbances

Of the total sample (*n* = 374), 237 participants (63.4%) reported having sought care from one or more healthcare providers for sleep disturbances (see Table 3.3). As summarised in Table 3.3, the number of healthcare providers consulted were distributed across a range of 1-8 (*Mdn* = 2.0), with most participants having consulted either one (23.2%), two (30.8%) or three (20.7%) healthcare providers for their sleep concerns.

Table 3.3

Number of Healthcare Providers Consulted for Sleep Disturbances

Variable	*n*	%	*M*	*SD*	*Mdn*	Range
Number of health providers consulted	237		2.7	1.6	2.0	1-8
1	55	23.2				
2	73	30.8				
3	49	20.7				
4	27	11.4				
5	16	6.8				
6	11	4.6				
7	3	1.3				
8	3	1.3				

3.6.2 Types of Healthcare Providers Consulted for Sleep Disturbances

Table 3.4 shows the types of healthcare providers consulted, and the proportion of participants who had consulted each provider at any point in time. Nearly all participants who sought professional care (*n* = 237) had reported consulting a general practitioner (GP) for sleep disturbances at some point in their healthcare journey (98.3%). Over half (52.7%) reported consulting a mental health professional, and nearly one-third (32.9%) reported consulting a gynaecologist. In total, the majority (70.4%) of participants sought care from at least one allopathic practitioner at some point in their healthcare journey, whereas 29.6% of participants sought care from at least one complementary and alternative medicine (CAM) professional for their sleep disturbances.

Table 3.4

Healthcare Providers Consulted for Sleep Disturbances

Healthcare Provider (*n* = 237)	*n*	%
General Practitioner	223	98.3
Other primary health provider	42	17.7
Gynaecologist	78	32.9
Other medical specialist	51	21.5
Mental health professional	125	52.7
Natural health professional	40	16.9
Body therapist	52	21.9
Dietician	22	9.3
Other[a]	4	1.7

Note. [a]*"Other" included* occupational therapists (*n* = 2), a psychiatrist (*n* = 1) and a physiotherapist (*n* = 1). Participants could select multiple healthcare providers that they had seen.

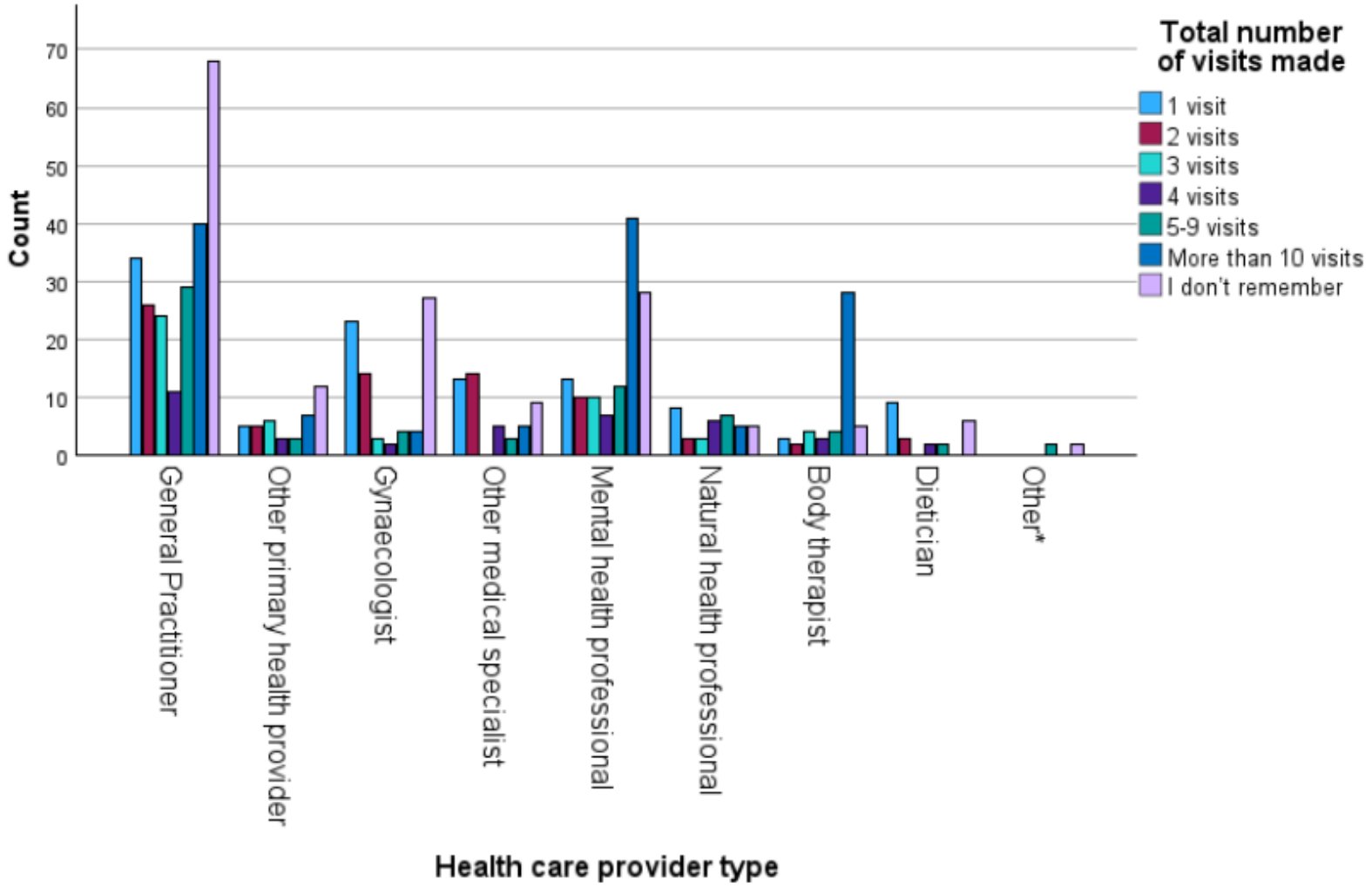
3.6.3 Number of Visits Made to Healthcare Providers

Figure 3.9 summarises the total number of visits made to each type of healthcare provider for sleep disturbances. The total number of visits made to general practitioners (GPs) ranged from one to more than 10. However, a substantial proportion of these participants (*n* = 68, 29.3%) reported that they did not remember how many visits they had made to a GP. Mental health professionals were also frequently consulted. The majority of those who sought help from a mental health professional reported making more than 10 visits (*n* = 41, 33.9%), while a smaller but noticeable proportion of participants (*n* = 28, 23.1%) did not remember how many visits they had made. Similarly, most participants who visited a gynaecologist reported not recalling how many appointments they attended (*n* = 27, 35.1%), and a similar proportion reported visiting only once (*n* = 23, 29.9%). A more distinct difference was observed in those who visited a body therapist, where a noticeable proportion of participants reported making more than 10 visits for their sleep disturbances (*n* = 28, 57.1%). Natural health professionals and dieticians were most commonly consulted on a single occasion for sleep-related concerns. Approximately one fifth (*n* = 8, 21.6%) reported

visiting a natural health professional once, and approximately two fifths (*n* = 8, 40.9%) reported a single visit to a dietician.

Figure 3.9

Total Number of Visits Made for Sleep Disturbances by Healthcare Provider Types



*Note. * "Other" was made up of occupational therapists (n = 2), a psychiatrist (n = 1) and a physiotherapist (n = 1).*

3.6.4 Types of Support Provided to Participants by Each Healthcare Provider

Table 3.5 summarises the types of support that participants were given by each healthcare provider. Lifestyle management tools were reported by all healthcare provider types and representing the highest proportions of votes in GPs (55.8%), mental health professionals (68.6%) and medical specialist (51.0%) and gynaecologist (41.6%) categories. Diet advice represented second highest proportions of votes in gynaecologists (36.4%) and medical specialist (36.7%). Notably, other primary healthcare providers (e.g., a nurse or pharmacist, as per the survey question wording), were most frequently reported to provide natural medicine advice (41.5%).

Among all the healthcare provider types, GPs were the most frequently reported to provide pharmacological support. These included sleeping medication (45.5%), melatonin (45.9%), anti-psychotic medication (28.1%) and anti-depressant medication (43.3%).

A noticeable proportion reported that they had not received any support. These proportions ranged between 5.0% to 24.7% across provider types (see Table 6). Noticeably, nearly one quarter of participants (24.7%) received no support from a gynaecologist for their sleep concerns. The largest proportions of referrals came from GPs, gynaecologists and other primary health providers (11.7%, 17.1%, and 11.7%, respectively).

Overall, patterns among most healthcare providers aligned with their primary scope of care. Body therapists were most frequently reported to offer manual manipulation for sleep disturbances (73.5%), natural health professionals were most frequently reported to provide natural medicine (64.9%), and dieticians were most frequently reported to provide diet advice (72.7%). Mental health professionals most frequently provided lifestyle management tools (68.6%) and psychotherapy (54.5%) and were the primary providers of psychotherapy compared with all other types of healthcare providers. Referral to another health professional was reported among those who had sought support from ‘other primary healthcare providers’ (17.1%), followed by those who consulted general practitioners and gynaecologists (11.7%).

Table 3.5

Types of Support Given by Different Healthcare Providers

Types of support given	Provider type								
	General practitioner (*n* = 231)	Other primary health provider (*n* = 41)	Gynae[a] (*n* = 77)	Medical specialist (*n* = 49)	Mental health professional (*n* = 121)	Natural health professional (*n* = 37)	Body therapist (*n* = 49)	Dietician (*n* = 22)	Other[b] (*n* = 4)
	n (%)								
Sleep medication	105 (45.5)	6 (14.6)	6 (7.8)	9 (18.4)	20 (16.5)	-	-	1 (4.5)	-
Melatonin	106 (45.9)	5 (12.2)	9 (11.7)	7 (14.3)	13 (10.7)	1 (2.7)	1 (2.0)	1 (4.5)	-
Antipsychotic medication	65 (28.1)	3 (7.3)	3 (3.9)	7 (14.3)	24 (19.8)	-	-	-	1 (25.0)
Antidepressant medication	100 (43.3)	5 (12.2)	12 (15.6)	11 (22.4)	31 (25.6)	-	-	1 (4.5)	-
Medical cannabis	22 (9.5)	3 (7.3)	2 (2.6)	3 (6.1)	2 (1.7)	6 (16.2)	-	1 (4.5)	-
Natural medicine	20 (8.7)	17 (41.5)	6 (7.8)	7 (14.3)	13 (10.7)	24 (64.9)	4 (8.2)	4 (18.2)	-
Lifestyle management tools	129 (55.8)	16 (39.0)	32 (41.6)	25 (51.0)	83 (68.6)	18 (48.6)	13 (26.5)	11 (50.0)	3 (75.0)
Diet advice	73 (31.6)	12 (29.3)	28 (36.4)	18 (36.7)	30 (24.8)	17 (45.9)	8 (16.3)	16 (72.7)	1 (25.0)
Psychotherapy	31 (13.4)	2 (4.9)	2 (2.6)	11 (22.4)	66 (54.5)	-	1 (2.0)	-	-
Manual manipulation	7 (3.0)	-	3 (3.9)	2 (4.1)	2 (1.7)	14 (37.8)	36 (73.5)	-	1 (25.0)
Referral	27 (11.7)	7 (17.1)	9 (11.7)	4 (8.2)	2 (1.7)	-	-	2 (9.1)	1 (25.0)
Other	12 (5.2)	3 (7.3)	14 (18.2)	11 (22.4)	5 (4.1)	1 (2.7)	9 (18.4)	1 (4.5)	-
None	16 (6.9)	6 (14.6)	19 (24.7)	9 (18.4)	6 (5.0)	2 (5.4)	4 (8.2)	2 (9.1)	-

Note. Each participant could select more than one type of support given, per healthcare provider. [a] "Gynae" = gynaecologist. [b] "Other" = occupational therapists (*n* = 2), a psychiatrist (*n* = 1) and a physiotherapist (*n* = 1).

3.7 The Four Most Common Healthcare-Seeking Journeys

Figure 3.10 shows a healthcare journey map, derived from participants' responses about their healthcare access and treatment, as described in Section 2.9. This journey map follows the sequential pathway of healthcare providers who participants visited when seeking support for their sleep disturbance. This journey map reads from left to right, showing the first, second, and third provider visited via the most commonly reported pathways. Satisfaction ratings of the care received and perceived effectiveness of care appear within the box for each healthcare provider.

In the text below, descriptions of the journey map summarise the four most commonly accessed healthcare pathways from which participants sought care. Other healthcare pathways were reported by participants, and are illustrated in Figure 3.10 with fewer frequencies. Other healthcare providers with fewer frequencies were collapsed into one group per point of access, as seen in boxes titled "other" in Figure 3.10. The four most common healthcare pathways described in the text below include the following:

1) General practitioner to mental health practitioner to gynaecologist
2) General practitioner to gynaecologist to other medical specialist.
3) General practitioner to other medical specialist to mental health professional.
4) Mental health professional to general practitioner to other primary health provider

3.7.1 The Most Common Healthcare Pathway: General Practitioner to Mental Health Professional to Gynaecologist

Of those who sought professional healthcare (*n* = 237), the most common healthcare pathway involved participants first consulting a GP (*n* = 202, 85.0%), followed by a mental health practitioner (*n* = 63, 32.7%), and subsequently a gynaecologist (*n* = 12, 19.7%). Among those who first consulted a GP, satisfaction with care ratings were predominantly negative, with the largest proportion of participants reporting as being dissatisfied with their general practitioner (*n* = 78, 39.2%). Ratings of perceived treatment efficacy for these participants show similar patterns, with

approximately two-thirds reporting that their treatment was not effective (*n* = 131, 65.8%), whereas a substantially smaller proportion reported that it was effective (*n* = 18, 9.0%).

Nearly one third of participants who first consulted with a GP (*n* = 202), subsequently consulted a mental health professional (*n* = 63, 32.7%) for their sleep disturbance. Within this subgroup, nearly half (*n* = 31, 49.2%) reported being satisfied with their care from a mental health professional. Perceived treatment efficacy within this subgroup was most frequently reported as being not effective (*n* = 35, 54.8%), compared with effective (*n* = 5, 7.9%).

Among those who first consulted a GP (*n* = 202), followed by a mental health professional (*n* = 63), 19.7% subsequently consulted a gynaecologist (*n* = 12). Satisfaction ratings in this subgroup were predominantly reported as being neural (*n* = 5, 41.7%). None of this subgroup reported care as effective, and most reported care as not effective (*n* = 8, 66.7%).

3.7.2 The Second Most Common Healthcare Pathway: General Practitioner to Gynaecologist to Other Medical Specialist

The second most common pathway involved participants consulting a GP in the first instance, followed by a gynaecologist, and subsequently another medical specialist. As noted above, most respondents from this group reported as being dissatisfied with care, and receiving ineffective support. Among those who first visited a GP (*n* = 202), 16.3% subsequently consulted a gynaecologist (*n* = 33). Of this subgroup, most (48.5%) reported as being dissatisfied with care (*n* = 16). The perceived efficacy ratings of this subgroup were most frequently reported as being not effective (*n* = 24, 72.7%).

Among those who first consulted a GP, followed by a gynaecologist, nearly one quarter (24.2%) subsequently consulted another medical specialist (*n* = 8). Of these participants, half (50.0%) reported neutral satisfaction with care (*n* = 4), and most (87.5%) reported highly effective treatment (*n* = 7).

3.7.3 The Third Most Common Healthcare Pathway: General Practitioner to Other Medical Specialist to Mental Health Professional

The third most common healthcare pathway included consulting a GP, followed by another medical specialist, then a mental health professional. As noted above, those who first consulted a GP showed varied levels of satisfaction and efficacy. Among those who consulted with a GP in the first instance (*n* = 202), 10.4% subsequently consulted another medical specialist (*n* = 20) in the second instance. Of these respondents, half (50.0%) reported dissatisfaction with care (*n* = 10), and approximately one third (30.0%) reported their satisfaction level as neutral (*n* = 6). Efficacy ratings within this subgroup were predominantly reported as not effective (*n* = 13, 65%). For those in this healthcare pathway who consulted a mental health professional in the third instance (*n* = 7, 35.0%), the majority (71.4%) reported care as satisfactory (*n* = 5), and most (71.4%) reported effectiveness as being moderate (*n* = 5).

3.7.4 The Fourth Most Common Healthcare Pathway: Mental Health Professional to General Practitioner to Other Primary Health Provider

Figure 3.10 illustrates that the fourth most common healthcare pathway involved seeing a mental health professional, followed by a GP, followed by another primary health provider. Compared with the first three most common healthcare pathways beginning with a consultation with a GP, much fewer participants consulted with a mental health professional (*n* = 13, 5.5%) in the first instance. Among these participants, the majority subsequently consulted with a GP (*n* = 12, 92.3%), with most reporting care as dissatisfactory (*n* = 5, 41.6%), and not effective (*n* = 8, 66.7%). A small proportion (*n* = 3, 25.0%) of participants in this care pathway consulted with another primary health provider in the third instance. Neutral satisfaction ratings were reported by most (*n* = 2, 66.6%), and most rated efficacy as not effective (*n* = 2, 66.6%). However, frequencies were very small.

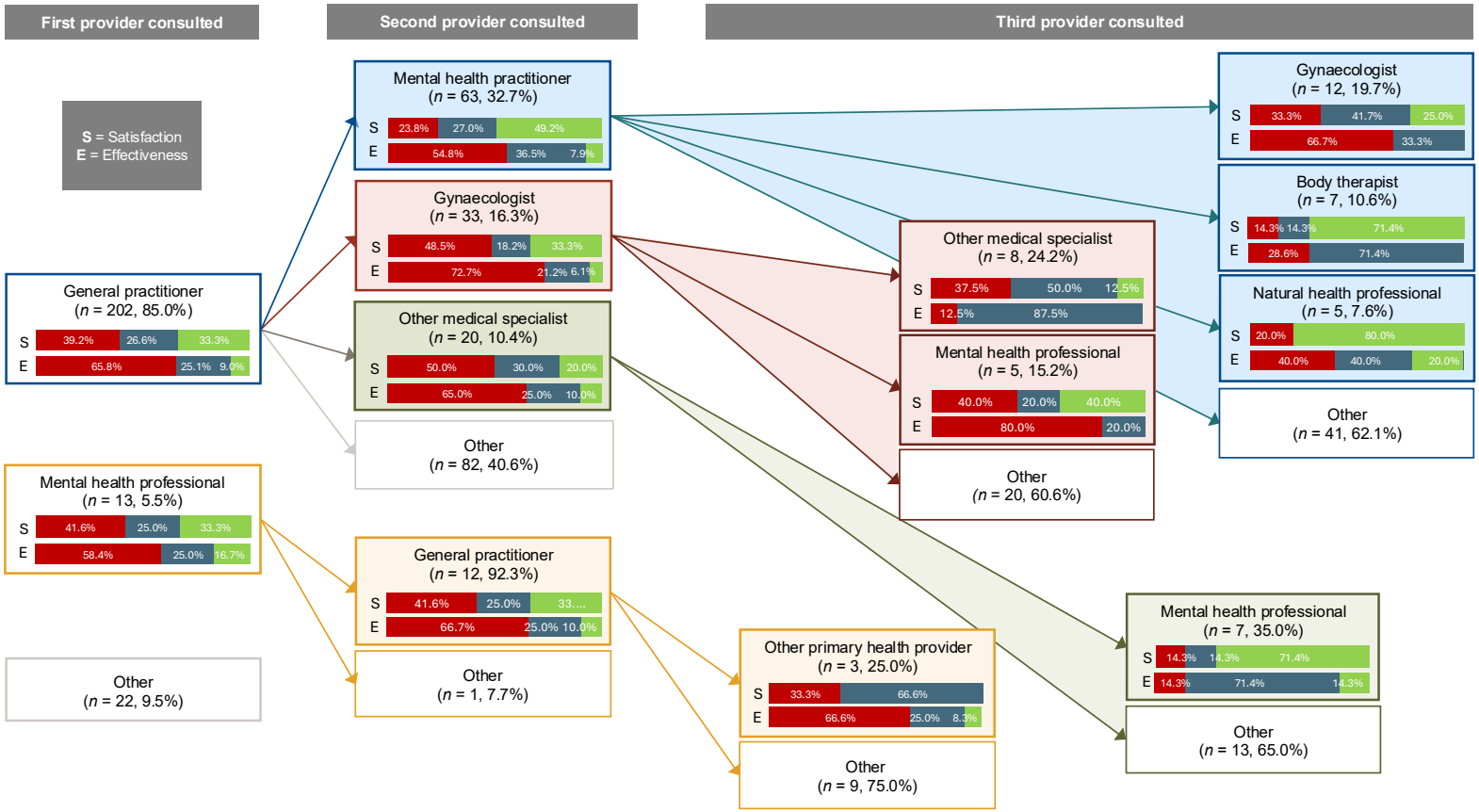
3.7.5 Patterns Across the Four Most Common Healthcare Pathways

As illustrated in Figure 3.10, regardless of the pathway, GPs were the most frequently consulted provider. GPs were typically consulted at the first stage of healthcare access (85%), with three of the four the most common pathways beginning with a GP consultation. In the pathway in which mental health professionals were consulted first, most participants (92.3%) subsequently consulted a GP in the second instance.

In the four most common healthcare pathways, some respondents only saw one provider, with fewer seeking care from a second and third provider. Dissatisfaction and low perceived treatment efficacy were frequently reported at the first stage of access, particularly among those who had initially consulted with a GP. Similar patterns were observed at the second stage of access. Healthcare specialists (e.g., other medical specialists, gynaecologists), as opposed to generalists (e.g., general practitioner) were more commonly visited secondly or thirdly. Mental health professionals appear to be consulted at some point in every stage of access, and receive collectively higher proportions of satisfaction ratings when compared to any other provider type, although the perceived efficacy ratings were mostly reported as modest. Allopathic health providers were accessed at all stages of the healthcare journey, whereas CAM providers (natural health professional, and body therapist) were accessed in the third successive stage of consultation, and were not in any of the four most common healthcare pathways.

Figure 3.10

Sequence of Healthcare Providers Accessed for Sleep Disturbances with Distribution of Satisfaction Ratings at Each Access Point



Note. This flowchart shows the sequential order of healthcare providers consulted for sleep-related concerns. The most reported healthcare journeys are depicted by arrows which follow the sequence of participants' healthcare access from left to right. Participants' satisfaction with care and efficacy ratings are shown in the stacked bar graphs (red: dissatisfied; blue: neutral; green: satisfied). "Other" boxes without bar graphs indicate the remaining frequency data, which has been collapsed into one group, at each point of access across both healthcare pathways.

3.8 Participants Who Did Not Seek Professional Healthcare

Of the total sample (*n* = 374), 117 participants (31.3%) reported not seeking professional healthcare for their sleep disturbances. These participants reported on the barriers to sleep-related healthcare that they had faced, which are summarised in Table 3.6. Over three-quarters of participants (77.8%) reported perceiving their sleep concerns as not serious enough to warrant professional care, and over half (57.3%) reported attempting self-management first. Smaller but substantial proportions reported they didn't think healthcare providers would help them (42.7%) or that they had negative experiences with healthcare providers in the past (29.9%).

Table 3.6

Barriers Faced by Those Who Did Not Seek Professional Healthcare for Sleep Disturbances

Barriers faced (*n* = 117)	*n*	%
Cost was too high	22	18.8
Worried asked something I didn't want to answer	8	6.8
Concerns about side effects/adverse reactions	20	17.1
Sleep concerns not serious enough	91	77.8
Trying to manage it on my own first	67	57.3
Negative experiences in the past	35	29.9
Didn't think it would help	50	42.7
Didn't know who to consult	24	20.5
No time to make appointment	9	7.7
Felt embarrassed or ashamed	13	11.1
Other[a]	14	12.0

Note. Participants could select multiple barriers to care, per each item listed.

[a] "Other" barriers that participants reported: "I didn't associate it with endometriosis at the time", "Can never get an appointment and I don't even know my doctor", "I have previously done shift work so felt that not ever feeling like I've had enough sleep is down to the irregularities of the shift pattern, however I have been on a Monday to Friday regular day hour pattern for the last 15 months and still feel just as exhausted as I did when doing shift patterns. I felt it easier to fall asleep when I was on shifts compared to now.", "I felt as though deep-down sleep may have been the issue, but everything else (other symptoms) was what was contributing to it. So if I could sort other symptoms it would help?", "My sleep issues are linked to pain, it was hard enough to get an actual diagnosis for endo and sleep is not high on the symptoms list in terms of management", "[I] haven't thought of it as a symptom of anything", "All medications besides the

CBD oil have caused other issues in the past so I try to take no medications as they do more harm than good.", "Told to diet and exercise to fix issues", "Just with having endometriosis and all the symptoms that come with - sorting out my sleep has been least prioritised", "I didn't know that poor sleep was associated with endometriosis", "I felt like I can only have one issue with my GP and that's all I'm allowed (self-imposed)", "I worked shift work and didn't think it was a part of my symptoms", "I didn't think it was important".

3.9 Participants' Self-Help Strategies and Effectiveness Ratings

Participants who sought professional healthcare for their sleep concerns and those who did not reported using a variety of self-help strategies (see Table 3.7) to varying levels of effectiveness (see Table 3.8).

Table 3.7

Self-Help Strategies Used for Sleep Disturbances by Healthcare-Seeking Status

Self-help strategy used	Sought professional healthcare (*n* = 237)		Did not seek professional healthcare (*n* = 117)	
	n	%	*n*	%
Natural products	181	76.4	95	81.2
Sleep trackers	125	52.7	49	41.9
Smoking or vaping	23	9.7	6	5.1
Alcohol	28	11.8	8	6.8
Exercise	96	40.5	48	41.0
Yoga or Thai Chi	40	16.9	21	17.9
Self-care practices	186	78.5	91	77.8
Diet	149	62.9	59	50.4
Other [a]	32	13.5	18	15.4
None	4	1.7	2	1.7

Note. Participants could select multiple self-help strategies each.

[a] "Other" self-help strategies that participants reported included pharmacological approaches (e.g., melatonin, over-the-counter sleep medication, medical cannabis), relaxation-based approaches (e.g., guided meditation, hypnosis, podcasts, white noise), heat-based strategies (e.g., hot water bottles), lifestyle modification (e.g., work schedule adjustment, reduced alcohol use) and natural supplements (e.g., Rongōa Māori and magnesium).

Table 3.8

Efficacy Rating of Self-Help Strategies Used for Sleep Disturbances by Healthcare-Seeking Status

Efficacy rating	Sought professional healthcare (n = 224)		Did not seek professional healthcare (*n* = 114)	
	n	%	*n*	%
Strongly disagree	16	7.1	6	5.3
Somewhat disagree	47	21.0	22	19.3
Neither agree nor disagree	60	26.8	36	31.6
Somewhat agree	94	42.0	48	42.1
Strongly agree	7	3.1	2	1.8

Note. The survey question read "My self-help strategies have been effective in managing my sleep concerns".

3.9.1 Participants' Reported Use of Self-Help Strategies

Table 3.7 shows that in both groups of participants (those who did and those who did not seek professional healthcare), only 1.7% reported using none of the listed self-help strategies. High frequencies were observed across multiple self-help categories in both groups. The most common self-help strategies were similar in both groups, being self-care practices (reported by 78.5% of those who sought healthcare, and by 77.8% of those who did not) and natural products (76.4% and 81.2%, respectively). The use of diet and sleep trackers was more frequently reported by those who sought professional healthcare compared to those who did not (62.9% and 52.7% respectively). Smoking and vaping, and alcohol use were reported by a minority of participants in both groups.

3.9.2 Participants' Reported Efficacy Rating For The Self-Help Strategy Used

As shown in Table 3.8, the perceived effectiveness of reported self-help strategies was similarly clustered across the healthcare-seeking group. Responses were concentrated in the middle categories, where most participants reported self-help strategies as being somewhat effective, neutral, or somewhat ineffective. Strong endorsement either way was uncommon in both groups. Almost half of the participants

in both groups reported that their self-help strategies were somewhat effective or strongly effective (45.1% among those who sought professional healthcare, and 43.9% among those who did not seek professional healthcare).

3.10 Reflexive Thematic Analysis Findings

Reflexive Thematic Analysis of open-ended survey responses explored how participants made sense of sleep problems in relation to their health, and how they experienced the journey of seeking professional healthcare for their sleep concerns. Two key themes were constructed, which captured patterns of meaning across the dataset: The misalignment between the lived and clinical legitimacy of sleep concerns, and the perceived limits of the scope of sleep care shape engagement and responsibility.

Theme One explores how sleep is understood as central to wellbeing, and how healthcare responses are experienced as limited and inconsistent with lived experiences. Following this, Theme Two explores how sleep-related healthcare is also experienced as limited and how this shapes involvement with, and responsibility for, sleep care. Table 3.9 represents demographic, endometriosis and sleep disturbance information for each participant whose quotes were included in the findings.

Table 3.9

Demographics and Basic Statistics of Participants Quoted in Thematic Analysis

Participant identifying number	Age	Time since onset of endometriosis symptoms	Time since onset of sleep disturbance	Sleep severity category[a]	Endometriosis-related quality-of-life impairment[b]
	Years	Years	Years	Category	EHP-5 score
		Theme One			
106	35	11-20	11-20	Moderate	55
250	53	> 30	21-30	Severe	60
365	36	11-20	1-2	Mild	45
506	32	21-30	11-20	Moderate	80
147	37	11-20	> 30	Moderate	65
296	31	6-10	21-30	Severe	70
532	35	11-20	11-20	Moderate	80
511	41	21-30	21-30	Moderate	85
435	28	11-20	11-20	Normal	55
427	40	21-30	3-5	Moderate	70
292	43	3-5	3-5	Normal	85
543	37	11-20	11-20	Mild	50
390	26	11-20	6-10	Moderate	70
98	31	1-2	< 1	Moderate	70
301	34	11-20	> 30	Severe	35
553	42	21-30	11-20	Moderate	70
491	24	11-20	11-20	Mild	60
209	24	11-20	11-20	Moderate	80
321	28	11-20	11-20	Moderate	60
		Theme Two			
56	32	11-20	11-20	Mild	60
482	21	3-5	11-20	Mild	65
222	21	6-10	3-5	Moderate	75
52	33	11-20	6-10	Moderate	75
492	24	6-10	6-10	Moderate	50
264	31	6-10	21-30	Moderate	80
307	35	3-5	11-20	Severe	70
127	27	3-5	21-30	Moderate	80
38	27	6-10	11-20	Mild	60
284	22	11-20	6-10	Moderate	80
238	32	11-20	21-30	Moderate	70
205	21	11-20	1-2	Moderate	55
549	27	11-20	11-20	Severe	75
167	21	6-10	22-10	Mild	55
09	24	11-20	11-20	Mild	30

Participant identifying number	Age	Time since onset of endometriosis symptoms	Time since onset of sleep disturbance	Sleep severity category [a]	Endometriosis -related quality-of-life impairment [b]
	Years	Years	Years	Category	EHP-5 score
190	32	11-20	11-20	Moderate	65
549	27	11-20	11-20	Severe	75
214	21	3-5	11-20	Mild	65

Note. [a]Sleep severity is based on PROMIS-SD-8b T-scores, categorised as normal (T-scores = 0-54), mild (T-scores = 55-59), moderate (T-Scores = 60-69), and severe (T-scores = 70-100). [b]Endometriosis-related quality of life impairment shows EHP-5 scores, where higher scores indicate greater quality-of-life impact, ranging from 0 (lowest impairment) to 100 (greatest impairment).

3.10.1 Theme One: "It's just not worth the discussion": There is Misalignment Between the Lived and Clinical Legitimacy of Sleep Concerns

This theme is centred around a misalignment between how participants understand sleep difficulties and how sleep concerns are recognised in healthcare. Participants consistently described sleep as interwoven with pain, mental health, quality of life and daily function. However, this understanding was not consistently matched in healthcare interactions, unless explicitly articulated and escalated.

Reflecting on their understanding of the experience of sleep, participants commonly described sleep disturbances as occurring in a "vicious" and "never-ending" cycle (P106; P250; P365), in which sleep difficulties exacerbated pain, mental distress, and daily tasks, which then further disrupted sleep. For example, one participant explained that "[they] need sleep to reduce pain, but can't sleep due to pain, then struggle through the day" (P506), and another described a "…lack of quality sleep affects all aspects of life." (P147). In their accounts, participants positioned sleep as both central to the lived experience of endometriosis and as a legitimate and consequential health concern. As one participant summarised **"**You cannot heal without good rest" (P296).

Across accounts, participants demonstrated confidence in their understanding of sleep experiences and in what might be needed to support improvement (e.g., "… I know what I'm going through and what I think could help" P532). However, many of these accounts simultaneously expressed a desire for it to be recognised in the

healthcare encounter, as reflected in statements such as "… We know our own bodies, please listen to our symptoms" (P511). These reflections demonstrated that participants considered sleep disturbances as warranting clinical attention, but that this was not automatically given.

Despite sleep's central role in participants' experiences, many recount healthcare appointments where sleep was perceived to be poorly understood or low on a priority list. Several reported that sleep was not inquired about in consultations, which participants interpreted as their health providers seeing sleep as being of low priority. For example, one participant noted, "my sleep quality has never once been brought up in regard to my endo, not even by my diagnosing gynae" (P435). Another described sleep as "really the least of my GP's concerns" despite its "detrimental effect on my general well-being" (P427). Likewise, another participant reflected that sleep problems "impact every element of my life yet [aren't] taken seriously enough" (P292). Together, sleep was illustrated to not be consistently treated as clinically worthy of attention.

Participants' descriptions of their experience also demonstrated that health professionals' priorities were perceived to lie elsewhere. It was frequently reported that clinical focus was directed toward pain, menstruation and endometriosis lesions, rather than sleep, as reflected in accounts such as "professionals are fixated on the endo and forget about all the other things you're trying to explain that's going on for you such as trouble sleeping" (P543), and "It's been pushed to the side to focus on my menstrual issues first" (P390). The prioritisation of other symptoms, particularly of those stereotypically associated with endometriosis, appeared to make sleep concerns seem comparatively illegitimate.

Misattribution of sleep issues as mental health was commonly described by the participants and was experienced as undermining the legitimacy of sleep concerns. For example, one participant explained "Doctors just presume it's due to me having anxiety, but I think it's the sleep issues causing the anxiety, not the other way around" (P98), while another stated, "My concerns were never taken seriously, nor addressed. I was consistently told it was a mental health issue" (P301).

Lastly, participants describe how escalation was often necessary for sleep concerns to be recognised as clinically worthy. This included many visits to medical professionals, explicit emphasis on the impacts of sleep issues, or experiencing escalation of symptoms that progressed without resolution, sometimes to the point of acute medical events, as one participant reflected, “I really only got taken seriously when I had a seizure… that’s when [the neurologist] started focusing on sleep dysfunction” (P553). Another participant stated, “I had to state that my sleep was impacting my life so badly that it impeded study and work before I got any meaningful help” (P491). Another noted that in “both conversations with the general practitioner and specialist, I have had to bring up my sleep issues.” (P206). In contrast, some participants chose not to raise sleep concerns altogether. Rather than escalating the issue further, some disengaged from the discussion in anticipation of non-recognition. One participant reflected, “it’s just not worth the discussion” (P321). Altogether, these experiences illustrate that legitimacy was not automatically afforded and often required escalation for sleep disturbances and their impacts to be acknowledged, sometimes to the point of disengagement altogether.

3.10.2 Theme Two: “I’ve had to hodge-podge techniques together”: Perceived Limits of the Scope of Sleep Care Shape Engagement and Responsibility

This theme is centred around how participants' experiences of sleep-related healthcare were shaped by the perceived limits of what healthcare could realistically offer for sleep difficulties in the context of endometriosis. Across accounts, sleep care was described as narrow and limited in scope, was associated with unwanted trade-offs and often offered limited resolution. Over time, these experiences appeared to shape participants’ expectations of healthcare and shift responsibility for managing sleep onto the individual.

Participants commonly described engaging with healthcare for sleep as offering limited viable options. Sleep care was frequently experienced as ineffective, with one participant saying, “There’s very little suggestion that will actually work” (P56).

Across accounts, the available scope of sleep care was most often described as limited to medication prescriptions or sleep hygiene advice. These options were frequently framed as insufficient compared to the severity of the sleep difficulties experienced, as shown by one participant who stated “I feel like I'm going crazy from lack of sleep and it’s almost like [health professionals] go ‘So you can’t sleep? Take a bath or drink tea’, like they haven’t heard anything you’ve just said” (P482). This perception contributed to sleep care being experienced as shallow, relative to its impact.

Medication was frequently described as providing some degree of relief, but this was often accompanied by unwanted trade-offs that limited its utility. Participants expressed unwanted side effects, financial costs, or short-lived benefits that often outweighed longer-term value and use. For example, one participant described stopping taking prescribed medication because it “would help but… affect[ed] my memory and emotional state” (P222), and another because “Zopiclone turn[ed] me into a zombie” (P52). Another participant reflected that sleeping pills “helped for a short amount of time, but they had a lot of side effects” (P492). Financial cost was also described as a barrier, with multiple participants wishing that melatonin in particular “wasn't so expensive. It's a great tool, but the cost is a massive barrier.” (P264).

Alongside these compromises, medication was also often framed as a short-term or masking approach to long-term sleep difficulties, with many participants expressing desire for a solution that doesn’t only control their symptoms, such as wishing for a “root cause, and not just put “band-aids” (A.K.A. meds) on it” (P307), and wanting valuable support “rather than masking everything with medication” (P127). These accounts detail how available medical intervention was experienced as constrained and not without compromises, which shaped engagement with care.

Sleep hygiene strategies were frequently recounted as the primary example of non-pharmaceutical care offered. This was often perceived as insufficient and difficult to implement. Participants frequently described receiving advice they had already tried before, such as being told to “try to go to bed earlier, avoid using [their] phone and to exercise, as though [they] haven’t tried all of these and more” (P38). Another described

their discussion with a healthcare professional about sleep, which amounted to “just a lecture on sleep hygiene" (P284). Another recalled “breathing exercises and meditation don’t help me, but this is all I'm ever told to do” (P238). When these strategies did not work effectively at managing sleep concerns, participants often detailed feelings that the failure was attributed to not following the advice correctly. For example, one participant explained, "I was made to feel like my sleep difficulties are my own fault” (P205), while another described feeling blamed when they suggested lifestyle strategies did not work (P549).

> There felt like there was a blame placed that can be hard. As if I wasn't following advice correctly, and it was my fault for not sleeping or sleeping too late. I understand that I'm the one who does the "work" for the techniques, but if they didn't work, I was told I wasn't doing them properly or was lying. It was frustrating... (P549).

These experiences were described as particularly frustrating, given that the nature of sleep difficulties limited participants’ capacity to implement lifestyle changes, as reflected in statements such as “it’s so hard to make [sleep hygiene] changes when you don’t have the energy to do it” (P167).

Over time, repeated experiences of limited or ineffective care appeared to reshape participants’ expectations of what healthcare could offer them. Many appeared to reconsider their engagement with healthcare – either by disengaging from it entirely or turning toward self-management strategies as a rational response. Some participants describe anticipating that seeking help would lead to little benefit, with comments such as “I'll be told to figure it out on my own essentially" (P09) and “I don't bother getting medical help for sleep anymore because it's just gotten me nowhere” (P190). Others describe turning toward self-managed strategies, such as combining multiple self-care “hodge-podged techniques” together to find some improvement (P549) or conducting their own research to help manage sleep (P214). Together, these accounts show how perceived limits in the scope of sleep care shaped engagement, contributing to a shift in the responsibility of sleep management from healthcare to the individual.

Chapter Four: Discussion

This parallel convergent mixed-methods study sought to evaluate the current sleep health and explore the sleep-related healthcare decisions and experiences in people living with endometriosis (PLWE) in Aotearoa New Zealand (AoNZ). Guided by a critical realist ontology and a feminist critical health epistemological lens, this study examined both individual experiences and the broader structural healthcare context in which they occur. The following chapter integrates the quantitative and qualitative findings and examines them in detail.

4.1 The Clinical Context of Participants:

To contextualise the study population, this sample was primarily composed of reproductive-aged adults, with a median age of approximately 30 years, reflecting an age population most commonly affected by endometriosis (Johnson et al., 2017). The ethnic distribution of participants was broadly comparable to nation population distribution, with proportions of Māori and European similar to those reported in recent AoNZ consensus data (Stats NZ, 2023). While this finding does not claim representativeness, these demographic characteristics provide a relevant context for interpreting the findings within the broader AoNZ population.

In addition to the demographic context, the clinical presentation in this sample suggests a substantial illness burden and provides context for discussing the sleep-related findings within. Firstly, at the time of the survey, almost all (96.8%) of the sample were experiencing multiple endometriosis symptoms, most of whom reported suffering a pain-related symptom (pelvic pain or painful periods). Pain-related symptoms are characteristic of endometriosis (Johnson et al., 2017) and have long been recognised as associated with the condition (Ballard et al., 2008), so this finding was expected to be frequently reported. The severity of the current symptoms was most frequently rated at moderate and very severe, suggesting a high level of symptom burden at the time of the survey. The type of symptoms experienced and the severity ratings have similarly been described in other PLWE in AoNZ settings (Ellis et al., 2022).

The current comorbidity reports from participants in this sample were also prevalent, with 88.2% reporting having at least one, and a substantial proportion of these reporting having a mental health-related comorbid condition. Mental health conditions, such as anxiety and depression, have frequently been associated with PLWE (Wang et al., 2021), and symptoms of both depression and anxiety have similarly been found to be significantly associated with PLWE compared to controls (van Barneveld et al., 2022).

The distribution of endometriosis-specific quality-of-life impairment scores, as measured by the Endometriosis Health Profile (EHP-5), indicated that the majority of the sample experienced a significant burden from their symptoms on their daily life (Jones et al., 2004). Significant impairment to health-related quality of life has been widely reported in studies of PLWE (Álvarez-Salvago et al., 2020; Szypłowska et al., 2023), including in studies using the same EHP-5 measure specifically (e.g., González-Echevarría et al., 2019; Škegro et al., 2021). Interestingly, the EHP-5 scores from the current study spanned the full range of the scale, indicating that some participants experienced much less impairment than others. Although few, the participants who suffered less endometriosis-related quality of life impairment may reflect the few who did not report experiencing many symptoms that are known to be associated with poor quality of life (such as pain), or may reflect symptoms that are present, but the individuals are coping well. In research exploring the perspectives of individuals experiencing chronic pain, those who are able to accept their chronic pain and continue engaging with meaningful lifestyle activities, regardless of the severity of symptoms, report better emotional well-being and quality of life (Dempster et al., 2015; Kranz et al., 2010). In the context of these findings, the varied EHP-5 results may therefore reflect the coping strategies and participants' perspectives of their condition, regardless of their symptoms.

Many participants also reported currently taking analgesic medications and hormonal contraceptives for their endometriosis. This finding aligned with expectations, as these are common first-line symptom management approaches for endometriosis symptoms, according to AoNZ clinical guidelines (Ministry of Health, 2020).

4.2 The Role of Sleep Disturbances in the Experience of Endometriosis

The first objective of this study was to examine the current sleep of PLWE in AoNZ. On the basis of existing literature, it was hypothesised that sleep disturbances would be experienced as impacting the health, well-being, and daily function of individuals.

The first key, integrated finding of this study is that approximately 9 in 10 of this sample have clinically elevated sleep disturbances, and that these are often experienced as persistent, central, and impactful components of endometriosis. The high proportion of clinically elevated sleep disturbances observed in this sample is consistent with previous research reporting substantial sleep difficulties among PLWE (Baldi et al., 2025; Sumbodo et al., 2024; Zhang et al., 2024), many of which similarly used subjective measurements of sleep disturbances and sleep duration. The experiences of sleep disturbances amongst this sample are demonstrated in part by the qualitative findings, where many participants describe them as in tandem with endometriosis symptoms, rather than a stand-alone symptom, and as both fuelling and fuelled by other aspects of the chronic illness burden. As outlined in Chapter 1, the literature on sleep-related experiences in PLWE is limited. However, a recent qualitative study similarly reported that participants described their sleep disturbances as cyclical and intertwined with the experience of chronic fatigue related to endometriosis (Spyrelis et al., 2024).

Applying a social-ecological model of sleep health to this finding provides a useful framework for interpreting the severity of sleep disturbance findings in this study. As introduced in Chapter 1, this holistic model conceptualises sleep health as being influenced by individual, social and societal factors (Grandner, 2017). From a biological perspective, pain represents a well-documented and plausible mechanism through which sleep disturbances are linked to endometriosis. For example, chronic pain is understood to impair the ability to initiate and maintain sleep, while sleep disturbance may further increase pain sensitivity, reinforcing a bidirectional relationship (Andersen et al., 2018; Nunes et al., 2015). Previous research on PLWE has demonstrated that pain significantly worsens sleep disturbances (Baldi et al., 2025; de Souza, Vilella, et al., 2023; Sumbodo et al., 2024). In the context of this study's findings, the high

endorsement of pain symptoms and elevated quality-of-life impairment (EHP-5 scores) may plausibly further contribute to the observed severity of sleep disturbances. Qualitative findings further supported this interpretation, whereby pain is often described as reducing the quality of sleep, and sleep worsening pain, which ultimately has effects on daily function.

Psychological factors may also plausibly contribute to the sleep disturbance patterns observed in this sample. A meta-analysis study demonstrates that high levels of psychological stress are prevalent among PLWE, and identifies a strong relationship between stress and endometriosis disease stage (Brasil et al., 2020). Further, anxiety and fear of symptoms progressing have been identified as specific predictors of insomnia symptoms in PLWE, through which cognitive hypervigilance may interfere with sleep onset (Pickup et al., 2024). In the context of the present study, the high prevalence of reported mental health co-morbidity may therefore suggest an additional, secondary, and important pathway through which sleep disturbance patterns occur in this sample.

Sleep duration was also measured in this study to further examine the sleep disturbances in PLWE. The findings suggest that PLWE in this sample are 'short sleepers' (sleep duration that is less than 7 hours per night), according to general population guidelines (Hirshkowitz et al., 2015). Prior research examining sleep duration as a single measurement among PLWE (as opposed to within a questionnaire) remains slim; however, a study by Baldi et al. (2025) measured sleep duration amongst a sample of 169 PLWE to find that sleep duration fell within the recommended range of 7-9 hours, with no significant differences when compared to age-matched, healthy controls. While these findings differ from those of the current sample, several mechanisms may plausibly explain the slight difference in results. Firstly, despite finding adequate sleep duration in their sample, Baldi et al. (2025) find significant impairment across other sleep dimensions amongst their sample of PLWE. They found that sleep satisfaction, vigilance, and efficacy were significantly impaired, and concluded that sleep remains significantly disturbed among their sample PLWE. The highlights that sleep disturbances can manifest in multiple ways and are not solely reliant on duration alone. Secondly, sample characteristics between the two studies are likely relevant as well. For example, participants of the current study were recruited based on a history of, or

current experience of, sleep disturbances, meaning that they were more likely to have greater disturbed sleep, whereas Baldi et al. (2025) included participants who only required a diagnosis of endometriosis.

Furthermore, a conceptual lens known as the Sleep Opportunity, Need, and Ability (SONA) framework helps to further interpret the sleep duration findings of the current study. The SONA framework conceptualises sleep disturbance as a discordance between an individual's biological need for sleep, their opportunity to get healthy sleep, and their ability to maintain it (Scott & Perlis, 2025). Given the immune function demands related to inflammatory processes in PLWE (Irwin, 2019; Scott & Perlis, 2025), it is possible that PLWE have a greater sleep 'need' than general population norms. In light of this, the slightly short sleep durations observed in this study may represent a greater deficit than initially suggested.

Another key finding from the present study emerged from examining the relationship between sleep disturbance severity and other clinical variables. Findings show that greater sleep disturbance is associated with reduced sleep duration, indicating that the participants who experience more severe sleep disturbances also sleep fewer hours. Findings also indicate that participants with greater severity of sleep disturbances experience higher levels of endometriosis-related quality-of-life impairment. The differences in the relationship between sleep disturbance severity and quality of life become more pronounced at higher levels of sleep disturbance severity, indicating that participants who experienced greater severity of sleep disturbances also experienced more impairment in well-being and daily functioning. Significant relationships between sleep disturbances and impairment of quality of life have been widely reported in the literature on PLWE populations (Arion et al., 2020; Facchin et al., 2021) and in case-control studies (Álvarez-Salvago et al., 2020; Davie et al., 2020). More broadly, population research in AoNZ has similarly identified associations between self-reported sleep complaints with a wide range of poorer mental and physical health outcomes (Paine et al., 2019).

Interestingly, there was no significant difference in age across sleep disturbance severity categories. Limited research regarding age-related differences in sleep

amongst PLWE exists, although broader, population research documents many age-related disturbances in sleep among women in general (Carrier et al., 2017; Grandner, 2017). Yet, these patterns were not observed in the present study. One possible explanation for this may be the age distribution of this sample. The age range of participants in this sample was relatively small and mostly clustered around early thirties. This may have reduced the ability to detect age-related differences between sleep disturbance that may otherwise be present between young adults (18-40 years old) and middle-aged adults (40-60 years old) (Ohayon et al., 2004), as relevant to this study. It is also possible that the sleep difficulties of this sample may be due to illness-related factors, such as pain, that may exert a stronger influence on sleep disturbances than age, as shown in other studies (Andersen et al., 2018; Facchin et al., 2021).

Collectively, the integrated findings relating to the experience of sleep amongst this sample suggest that sleep disturbances occur within a constellation of endometriosis-symptom burden. This finding is supported by findings from other studies of sleep disturbances among PLWE (Arion et al., 2020; Baldi et al., 2025; Davie et al., 2020).

4.3 Healthcare Seeking Journeys for Sleep Disturbances

The second aim of this research was to explore the sleep-related healthcare journeys taken by PLWE in AoNZ. The third aim was to explore the lived experiences of these sleep-related healthcare journeys. As highlighted in Chapter 1, few studies on sleep-related healthcare journeys or experiences among PLWE exist. However, the broader literature on healthcare decisions, journeys and experiences among PLWE, and that of sleep-related care in other clinical populations, informed the hypothesis. It was hypothesised that PLWE with sleep disturbances may explore a range of management strategies to support their sleep concerns, and simultaneously experience difficulty in adequately managing their symptoms. It was also hypothesised that PLWE may find healthcare encounters challenging.

The key findings from this study suggest that PLWE in this sample actively seek healthcare for their sleep disturbances from a range of healthcare providers across

multiple health sectors, and that the experience of these healthcare journeys is often perceived as ineffective or unsatisfactory, often accompanied by themes of symptom dismissal, frustration and, in some cases, disengagement with healthcare. Findings also suggest that self-directed management strategies are an important and often necessary component of care for sleep disturbances. The following section discusses the key findings before presenting possible mechanisms for their emergence.

4.3.1 The Range of Healthcare Providers Across Multiple Health Sectors

Approximately 2 out of 3 participants in this study consulted one or more types of healthcare providers for their sleep disturbances. In the context of a sample with clinically elevated sleep disturbances and heightened quality-of-life impairment, this finding was expected. For instance, in other research, many individuals with endometriosis describe visiting healthcare providers for their symptoms (Metzemaekers et al., 2021). Prior research has also demonstrated that higher sleep severity was associated with more frequent healthcare use (Manocchia & Ware, 2001).

The common patterns of healthcare utilisation observed in this study progressed from generalist care (i.e., the majority consulted a GP in the first instance) to specialised care (i.e., mental health professionals, gynaecologists, or other medical specialists in subsequent visits). Many participants in this study followed healthcare journeys reflecting those typically associated with endometriosis care in AoNZ (i.e., consulting with a GP in the first instance, followed by consulting with a gynaecologist or other medical specialist in the second instance). This pattern has been observed in other qualitative research from AoNZ. Ellis and Wood (2025) find that nearly half of endometriosis patients had discussed accessing a gynaecologist via publicly funded healthcare pathways. Ellis and Wood (2025) suggest that this pattern likely reflects the typical order of the public healthcare system in AoNZ whereby GPs act as ‘gatekeepers’ and referrers to accessing publicly funded specialised care. This, and the general patterns observed in the current study, align with the recommended clinical progression of endometriosis care for primary care professionals in AoNZ (Ministry of Health, 2020). Therefore, the common patterns of healthcare observed in the present

study suggest that many PLWE are accessing public healthcare via endometriosis-related pathways in pursuit of support for their sleep disturbances.

A notable feature of the four most common healthcare pathways observed in this study was the relatively frequent consultations with mental health professionals. After initially consulting with a GP, care often diverged into that of a mental health professional. Mental health professionals also appeared at each stage of healthcare access within this sample, and, second to GPs, were among the most frequently consulted provider types, irrespective of the number of consultations. Mental health professionals may offer specialised services for sleep concerns such as cognitive behavioural therapy for insomnia (CBT-I). CBT-I is considered one of the first-line treatments for sleep concerns such as insomnia (BPAC NZ, 2017; Edinger et al., 2021). In AoNZ public healthcare, referrals to mental health professionals for CBT-I are reasonably expected. Therefore, it was reasonably expected that PLWE might have consulted mental health professionals for their sleep disturbances; however, the frequency of such consultations was higher than expected.

Alongside this, consultations with a mental health professional were accompanied by greater satisfaction scores compared to those of other provider types along the common healthcare pathways. Despite the frequency of visits and the slightly more satisfying experiences with a mental health professional, the perceived effectiveness ratings for mental health professionals remained mixed. In interpreting this finding alongside the qualitative findings of this study, a tension appeared. The qualitative themes show that many participants were frustrated when their sleep concerns were misattributed to a mental health cause. Taking this into account, these suggest that PLWE wouldn't seek care from mental health professionals. Other research similarly shows that sleep disturbances are frequently misattributed as mental health issues and treated as secondary concerns, as described in insomnia research by Davy et al. (2015).

One possible explanation for the higher satisfaction levels seen in mental health providers than expected, despite effectiveness ratings remaining low, may be due to the nature of mental health providers' care. Mental health consultations often involve

longer sessions and more opportunities for validation of experiences. Validation is an important aspect of care for individuals with chronic pain (Nicola et al., 2022). Nicola et al. (2022) propose that in order to achieve validation of pain, pain must be believed as true, accepted and expressed via explicit communication. Mental health professionals use communication styles that seek to understand experiences, which may have contributed to feelings of support. Therefore, it is plausible that relational aspects of mental healthcare, specifically, may have contributed to its frequent appearance among common care pathways and its greater satisfactory experiences, even when perceived effectiveness ratings remained varied.

4.3.2 Dissatisfaction and Perceived Effectiveness

The present study finds that higher dissatisfaction ratings and lower perceived effectiveness occur at the first points of the common healthcare journeys. This is particularly notable and suggests that many participants were unhappy with the care they received when seeking support in the first instance. Subsequent consultations appear similarly, with perceived effectiveness ratings remaining relatively low. Additionally, substantially fewer participants continued to subsequent stages of care after the first encounter with a healthcare provider. That is, although some continued seeking professional healthcare, many also disengaged from sleep-related healthcare after an initial consultation. This observation is interpreted alongside the qualitative findings, in which many participants expressed frustration with their healthcare interactions. Some described disengaging from care due to experiences of dismissal, disregard or feeling misunderstood, while others describe persevering despite unsatisfactory experiences in pursuit of symptom relief. Together, these findings suggest that early healthcare encounters may shape how PLWE experience healthcare and engage with future healthcare.

Experiences of feeling misunderstood and isolated in healthcare settings, are a common theme in endometriosis literature (Cole et al., 2021; Grogan et al., 2018), along with a desire to be heard, respected as experts in their experience, and acknowledged in medical healthcare encounters (Grundström et al., 2023; Harris et al.,

2025; Pettersson & Berterö, 2020). Long, dissatisfactory healthcare journeys are reported in other studies with PLWE, undertaken in the continued pursuit of symptom relief (Fernley, 2021; Pettersson & Berterö, 2020). In general populations, seeking healthcare for sleep disturbances similarly results in patterns of dissatisfaction (O'Regan et al., 2023).

Much of the dissatisfaction observed in this study may be due to the type of advice that participants received. Many participants reported that their healthcare providers offered pharmacological care and lifestyle management tools as their primary advice for sleep concerns. The generally mixed effectiveness ratings and the multiple healthcare providers consulted are considered alongside the qualitative findings, which suggest that such advice was inadequate to address sleep concerns and was often experienced as a dismissive form of care. The qualitative findings of this study further indicate that many PLWE withdraw from healthcare due to these perceived frustrations. This may reflect the amount of effort required to navigate healthcare and the difficulties associated with it. The need to advocate for oneself across multiple healthcare encounters until eventual concerns are granted recognition as legitimate was a core theme of this study's qualitative findings, and is also prominent in other qualitative research among PLWE (Young et al., 2020). Consequential disengagement from healthcare following dismissive encounters has also been described in other endometriosis research (Denny, 2009; Márki et al., 2022).

An explanation for these findings is that lifestyle management advice assumes individuals have behavioural control over their sleep routines, whereas PLWE might not, due to the burden of symptoms affecting daily function. In the context of a sample whose quality-of-life impairment decreases as sleep disturbances increase, adherence to lifestyle advice may be practically challenging, leading to the frustration observed among participants. Another explanation for this finding is that PLWE face many complex health-related decisions daily (Metzemaekers et al., 2021). From a broader perspective, the necessity that many women feel to have to advocate for their concerns to be heard in medical settings has been considered a form of exhaustion, described as ‘a third shift’ (Seear, 2009b). A qualitative study shows that in PLWE, significant effort is required to seek treatment options (O’Hara & Roufeil, 2024). Further, sleep

disturbances affect emotional brain function, thereby impairing complex health decision-making (Goldstein & Walker, 2014). Taken together, this may reflect dissatisfaction with the sleep-related care that was offered to participants of this study, as well as the withdrawal from professional healthcare observed.

4.3.3 Self-Directed Management

Most participants in this sample engaged in extensive self-directed use of self-management strategies for their sleep disturbances, as seen in a high rate of multiple strategies regardless of access to professional healthcare. Among those who did not seek professional help for their sleep issues, a large proportion reported preferring to manage their concerns independently. Many others reported rather trying to manage it on their own, and others didn't think professional healthcare would help. This observation suggests that PLWE may not see healthcare as necessary, or helpful for their sleep problems. Qualitative findings further describe how participants experimented with a mix of strategies to handle their concerns at home, often combining self-management techniques with professionally prescribed support, such as medication and self-care practices. These were often viewed as temporary "band-aid" measures, frequently accompanied by unwanted side effects, and sometimes considered insufficient or challenging to implement. The qualitative findings also suggest that many participants chose not to seek professional support because they believed it would not help, and others because of negative past experiences with healthcare.

In broader endometriosis experiences, research has shown that PLWE feel they need to "be [their] own doctor" (Young et al., 2020, p. 31). Similar 'mix-and-match' patterns of care are observed in the one and only study exploring fatigue-management amongst PLWE specifically (Sibande & Roomaney, 2022), and have previously been documented in the context of other chronic illnesses (Repping-Wuts et al., 2008) and in sleep care journeys for the general population (O'Regan et al., 2023). Overall, these findings indicate that self-management plays a key role in how PLWE manage sleep disturbances. Therefore, self-management strategies are both a preferred and

necessary form of care in a context where healthcare is often seen as unsatisfactory, inaccessible, and limited.

4.3.4 Explanatory Mechanisms for the Key Findings of the Healthcare Journey

Taken together, the key findings from the healthcare data in this study suggest that healthcare journeys for sleep disturbances involve diffuse pathways of care spanning multiple healthcare providers and sectors, indicating that there is no clear pathway of care for sleep disturbances in endometriosis. Qualitative findings deepen this interpretation by several accounts, indicating that sleep concerns were not raised or addressed in consultation at all. Findings therefore suggest that healthcare encounters, along with the type of care offered, may shape the experience of these journeys and, simultaneously, constitute an overlooked issue in healthcare.

The widespread use of self-management strategies alongside professional healthcare consultation suggests that care is not consistently adequate at supporting sleep disturbances among PLWE. Instead of reflecting resolution, the mixed-and-matched approach seen in this sample appears to represent attempts to manage ongoing or recurring symptoms. While the present study cannot determine whether sleep disturbances were inadequately treated, recurring, or resistant to interventions, the reliance on diverse simultaneous self-management strategies and professional healthcare consultation may reflect unmet needs within the healthcare system from the perspective of those who experience endometriosis.

A possible explanation for these findings may lie in the practical constraints on managing sleep disturbance in routine clinical practice. Healthcare professionals have relatively few forms of care that they can offer beyond pharmacological and behavioural interventions (Edinger et al., 2021; Sateia et al., 2017). These options are not always effective, are accompanied with risks, adverse effects and next-day impairments, and therefore are not always suitable or safe to prescribe (Campbell et al., 2023). Further, within an AoNZ context, there are very limited sleep specialists and specialised sleep services.

Formal medical training on sleep is also very limited. A recent study highlighted that sleep and circadian training in AoNZ and Australian medical schools consists of only four hours across courses (Bin et al., 2026). In the context of the present study, if sleep is not an issue that many healthcare professionals are trained in, many may not consider sleep disturbances as a possibility, or know how to effectively treat a patient presenting with sleep disturbances.

The knowledge of the healthcare provider can fundamentally shape patients' experiences with healthcare, as suggested in other endometriosis research, in which participants report that perceived gaps in provider competence lead to dismissive interactions and, therefore, act as barriers to care (Mikesell & Bontempo, 2023). Recent AoNZ research found that only 52% of GPs felt their knowledge of endometriosis, symptoms, and management was sufficient (Ellis et al., 2024). If sleep is not routinely recognised as associated with endometriosis or routinely addressed in healthcare encounters, these factors may compound to potentially create tension between the individual's expectations for care and what the provider knows and can assess and manage. This suggestion aligns with prior research suggesting that sleep-related issues are awkwardly situated between medical and behavioural health domains and are therefore frequently framed as a woman’s individual responsibility (Hislop & Arber, 2003).

Limited time during consultations with healthcare providers may also be a factor in the current studies findings, which observed themes of dissatisfaction with medical care. Research on PLWE shows that being rushed in medical settings adds to the feeling of dismissal (Bullo & Weckesser, 2021). Within these constraints, interactions may be perceived as unsatisfactory, with a shared confusion about where PLWE with sleep disturbances should be referred to, or what care they should be given to manage their care. Prior literature examining sleep care from both patient and provider perspectives similarly describes these limiting structural factors as influencing the negative experiences for both patient and provider (Haycock et al., 2021; O'Regan et al., 2023). Additionally, recent interviews with primary care practitioners for PLWE in AoNZ also find that GPs perceive many structural constraints that hinder their ability to adequately

support PLWE, such as a lack of time to build relationships and to adequately assess their concerns (Ellis & Wood, 2025).

4.4 Implications

The integrated findings from this study suggest two areas of importance regarding possible implications. The implications of these findings are considered at the individual and broader healthcare system levels.

4.4.1 Personal Level Implications

The clearest implication of these findings is for the individual's health, well-being, and daily functioning. If sleep disturbances lack a clear place within healthcare, or are inconsistently managed, they may perpetuate a cycle of symptoms that interact with one another and amplify the burden associated with the condition. The persistence of poor sleep health may also further impact the disease progression of endometriosis lesions themselves. For example, recent genetic and neuroendocrine research is showing evidence of a causal relationship between sleep disturbances and risk for endometriosis (Fang et al., 2025; Li et al., 2026), indicating that sleep may be an important modifiable factor in endometriosis disease pathogenesis and management.

In addition, there are potential functional consequences at the individual level. For example, living with endometriosis is already associated with a great financial burden, which often includes healthcare costs and treatment expenses (Tewhaiti-Smith et al., 2025). The presence of co-occurring sleep disturbances may further compound this challenge as PLWE explore many healthcare avenues in ongoing pursuit of symptom management. That is, additional time, finances, and cognitive demands may result.

The findings also highlight potential risks associated with a high reliance on self-directed management strategies. Many participants reported using natural products, self-care practices, sleep trackers and diet to manage their sleep concerns without professional guidance. With the rise of increasingly accessible online information about

health, such as social media content, promotions, anecdotal recommendations, and non-expert advice circulating about sleep care, people may encounter inaccurate, commercially biased, or non-evidence-based guidance on sleep. For example, in a recent study, popular YouTube videos about sleep were shown to exhibit signs of commercial bias, sponsored content and misinformed advice (Robbins et al., 2022). The adoption of misinformation from online sources may lead to unhealthy sleep practices and ultimately, poorer sleep health (Bragazzi & Garbarino, 2024). This is particularly relevant given that sleep disturbances themselves may impair emotional regulation and the ability to critically evaluate information, potentially making people with sleep disturbances less capable of discerning credible information and heightened emotional reactivity (Newbury et al., 2021).

Relatedly, an increased focus on the use of self-tracking devices for sleep may also pose a risk to PLWE. Excessive self-tracking and self-managing may contribute to maladaptive behaviour such as orthosomnia, defined as an anxiety-driven pursuit of 'ideal' sleep (Jahrami et al., 2023). Given that approximately half of the participants in this sample reported using sleep trackers, this may represent an additional way in which a well-intentioned self-management effort could inadvertently worsen sleep outcomes.

The tension between patients and their healthcare providers presented in this study may lead to increased disengagement from professional care and increased reliance on self-directed management, as the findings already suggest. Invalidating experiences between providers and patients can lead to a range of negative outcomes for patients (Bontempo et al., 2025). For example, the level of trust between the provider and patient has been highlighted as an important factor that can both be a barrier and a facilitator to PLWE experiences in healthcare (Joseph-Williams et al., 2014). If trust between the patient and the provider is not strongly felt for participants in this sample, it can erode the relationship and impact engagement with care. A recent study in AoNZ demonstrated that dismissal in healthcare encounters reflects power imbalances between patients and practitioners in PLWE, which can harm the individual's sense of self, change the patient's likelihood of seeking healthcare, and impair their ability to manage their condition (Ellis & Wood, 2025). Negative experiences may therefore lead

to increased scepticism toward health providers and negative perceptions of their ability to help manage symptoms, further worsening the burden on quality of life. If PLWE feel their concerns are invalid, they may stop raising them, leaving sleep issues hidden and untreated. In this study, qualitative findings suggest that those who repeatedly advocated for themselves received desired attention in medical settings regarding their sleep concerns. As such, those who have less time, money, access, health literacy or confidence may miss out on receiving important healthcare, in turn prolonging suffering and reinforcing existing inequities in how women's health concerns are addressed.

4.4.2 Implications For Public Health

The findings of this study may also have financial implications for the healthcare system and society at large. Although this study cannot determine how participants' consultations were accessed (e.g., privately or via publicly funded healthcare), the patterns observed indicate many points of engagement with healthcare services, without necessarily leading to satisfactory or sustained symptom improvement. Therefore, unclear pathways of care for sleep disturbances in PLWE may contribute to ineffective use of healthcare resources. Addressing gaps in women's health has been estimated to improve workforce participation, with potential global economic benefits (Panda, 2025). Endometriosis is already associated with a substantial financial burden to AoNZ (Tewhaiti-Smith et al., 2025). In an AoNZ context, previous research has calculated the potential financial benefit of treating adults with insomnia (O'Keeffe et al., 2012). This highlights the potential value of developing strategies to address sleep disturbances in PLWE.

4.5 Strengths of this Research

This study has several strengths. Firstly, this research provides novel insights into a significant, yet largely unexplored area of research, both in endometriosis and sleep-related fields. To date, few studies have examined sleep disturbances among PLWE in a AoNZ context, and none have explored how these individuals navigate healthcare

specifically for their sleep concerns. By exploring both sleep experiences and healthcare journeys of PLWE, this research extends beyond the current literature that primarily has focused on prevalence and impacts (e.g., Facchin et al., 2021; Sumbodo et al., 2024; Zhang et al., 2024) and into a more applied understanding of sleep in endometriosis.

Conceptually, this study contributes to the growing understanding of sleep disturbances as an embedded part of the experience of endometriosis, rather than a coincidental co-morbidity. This aligns with current literature (e.g., Sumbodo et al., 2024) and contributes both quantitative and qualitative findings that suggest how sleep is experienced in this population.

Methodologically, a key strength of this research lies in the study design and purpose-built survey development process. The mixed-method survey design was specifically tailored to answer the research question and fulfil the research aims. As such, it produced findings relevant to an AoNZ context. For example, multiple-choice questions used medications, health services and barriers to care that were relevant to AoNZ.

Another strength of this study lies in its use of validated and context-specific measurement tools. The inclusion of the EHP-5 provided a disease-specific overview of quality of life, rather than generic measures, which have previously been used in other research exploring sleep in PLWE (e.g., Facchin et al., 2021). Similarly, the PROMIS-SD-8b offered a psychometrically robust measure of sleep disturbances. To the best of my knowledge, this study is amongst the first to include the PROMIS-SD-8b in assessing sleep disturbances in PLWE.

4.6 Limitations

This study has limitations that should be considered when interpreting the findings. Including participants with a clinical diagnosis of endometriosis, rather than restricting the sample to laparoscopically confirmed cases, may have introduced heterogeneity and limited comparability with other studies of PLWE with surgical confirmation. However, this was considered appropriate, as it reflects contemporary

clinical practice in AoNZ and aligns with the theoretical perspective of this study, which acknowledges lived experiences as impactful and legitimate, even in the absence of often-inaccessible, often-invasive diagnostic confirmation.

The PROMIS-SD-8b had not yet been applied in endometriosis populations, which may limit comparability with existing studies using alternative sleep measures. However, the PROMIS-SD-8b demonstrated reliability, validity, and responsiveness in another study that included a large female health sample of 1022 women experiencing vasomotor symptoms (Avila et al., 2020; Schultz et al., 2023), and was selected for its ability to provide a broad multidimensional assessment of sleep disturbances.

A survey-based data collection method may limited opportunities for in-depth exploration and clarification of PLWE experiences compared to interview-based approaches. The wording of one of the two open-ended questions may have influenced the nature of the qualitative responses, prompting participants to emphasise the negative aspects of care. However, this was intentionally framed to identify areas of improvement that could be applied in real-world settings.

Finally, the use of convenience sampling and online recruitment may have introduced some degree of sampling bias. For example, participants who chose to participate in the survey may have been more likely to experience severe sleep disturbance symptoms, which could have influenced the patterns observed. However, this approach was chosen for its ability to access a broad sample. Additionally, the wording of the advertisement was carefully reviewed to ensure it was neutral and avoided leading.

4.7 Future Directions for New Research:

The findings of this study indicate that sleep may represent an important and potentially modifiable factor within the lived experience of the condition. As such, research examining management strategies specifically for PLWE may offer a meaningful avenue for enhancing the overall well-being of this population. One potential direction for future research is to investigate the role of educational interventions in improving sleep and healthcare experience outcomes in PLWE. Sleep

education has previously been shown to successfully improve sleep health dimensions and mental health in pregnant women in an AoNZ setting (Ladyman et al., 2020). Similar approaches may therefore be similarly beneficial to those experiencing endometriosis-related sleep disturbances and warrant further investigation.

Future research should also explore how sleep disturbances and sleep-related healthcare are experienced by PLWE across different ethnic groups in AoNZ. Existing AoNZ research indicate that Māori experience a higher prevalence of short (less than 7 hours) and long (more than 9 hours) sleep duration compared to non-Māori, which were not explained by socioeconomic and health factors (Paine & Gander, 2016), and that Māori experience significant inequities to sleep health across many sleep health dimensions (quality, alertness, timing, efficiency, duration) (Baddock et al., 2024). Given the long-standing inequities in general healthcare for Māori (Davis et al., 2006), it is important for future research to examine whether patterns and experiences of sleep and related healthcare differ across ethnic groups. Future research may explore how structural inequities shape healthcare access, engagement and sleep-related outcomes among a sample of Māori PLWE.

Another important direction of research is the role of the provider-patient relationship in shaping sleep-related healthcare for PLWE. In the present study, healthcare experiences were found to potentially influence how individuals manage their sleep concerns. Research in other contexts has demonstrated that the quality of the healthcare relationship may help improve treatment engagement and outcomes (Drossman & Ruddy, 2020). In the broader context of endometriosis, recent research has highlighted the need for improved care, including strengthening the relationship between providers and patients, and introducing more easily accessible specialists, such as endometriosis-focused GPs or nurses (Ellis & Wood, 2025). In the present study, the observed satisfaction levels during consultations with a mental health professional indicate that a particular aspect of the nature of care may be associated with higher satisfaction. Grundström et al. (2023) also suggest that validating and empathetic communication in healthcare settings improves the well-being of PLWE. Therefore, further research could build on Ellis and Wood (2025) recommendations and

explore what components of a healthcare relationship are effective, satisfactory, and adequate in sleep-related settings for PLWE.

The findings of this study also indicate a need for further research on the role of complementary and alternative medicine (CAM) for managing sleep disturbances among PLWE. The use of CAM practitioners was evident in the later stages of the most common healthcare journeys in this study, and perceived effectiveness ratings for consultations with CAM providers suggest their potential value for sleep-related concerns in PLWE. Other sleep-related research suggests that a combination of CAM alongside conventional care offers unique benefits to sleep disorders experienced by women (Frange et al., 2017). Therefore, future research may explore how PLWE with sleep disturbances engage with CAM in their care, how these approaches are perceived, and how they relate to existing gaps in conventional healthcare services.

Finally, further research is needed to better clarify the mechanisms behind sleep disturbances in PLWE. While pain and mental health co-morbidity are likely mechanisms, other factors, such as medication use, may be important to examine to understand the mechanisms driving SD in PLWE. The findings of the present study suggest that sleep disturbances were present in the context of a sample who had relatively high mental health co-morbidity and high medication use. Future studies could specifically examine how these common factors interact and influence sleep-related symptoms, experiences, and treatments in PLWE.

4.8 Conclusion

This mixed-methods study explored current sleep disturbances, sleep-related healthcare decisions, and experiences among people living with endometriosis in Aotearoa, New Zealand. The findings demonstrate that sleep disturbances are a substantial and embedded component of the experience of living with endometriosis, experienced as cyclical and inseparable, and are associated with differences in well-being and hours slept. However, despite this significance, sleep disturbances do not appear to be clearly recognised or prioritised within existing healthcare pathways.

Participants in this study actively sought healthcare for their sleep disturbances from multiple healthcare providers and sectors. Yet, experiences varied and were often accompanied by frustration, dismissal and invalidation. A substantial reliance on self-management strategies is also evident from the findings, demonstrated by a high proportion of use by most of the sample, regardless of professional guidance, which was due to perceived limitations of healthcare. Additionally, the health provider encounter was evident as an important aspect of the experience of healthcare for sleep disturbances and likely shaped subsequent engagement with healthcare for sleep.

These important findings contribute to a growing understanding that sleep disturbances are not only common but are a significant and contributing aspect of endometriosis that perpetuates a cycle of symptoms and contributes to impaired quality of life. At the same time, this study offers novel insights into how individuals with endometriosis manage their sleep concerns and suggests that sleep disturbances are structurally overlooked in AoNZ healthcare settings. Taking these findings into account, they highlight structural limitations within the AoNZ healthcare system and gaps in care for an already vulnerable and underserved population. Addressing these gaps will be a crucial step towards providing more responsive and holistic care that better reflects the lived realities of PLWE in AoNZ.

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Appendix A

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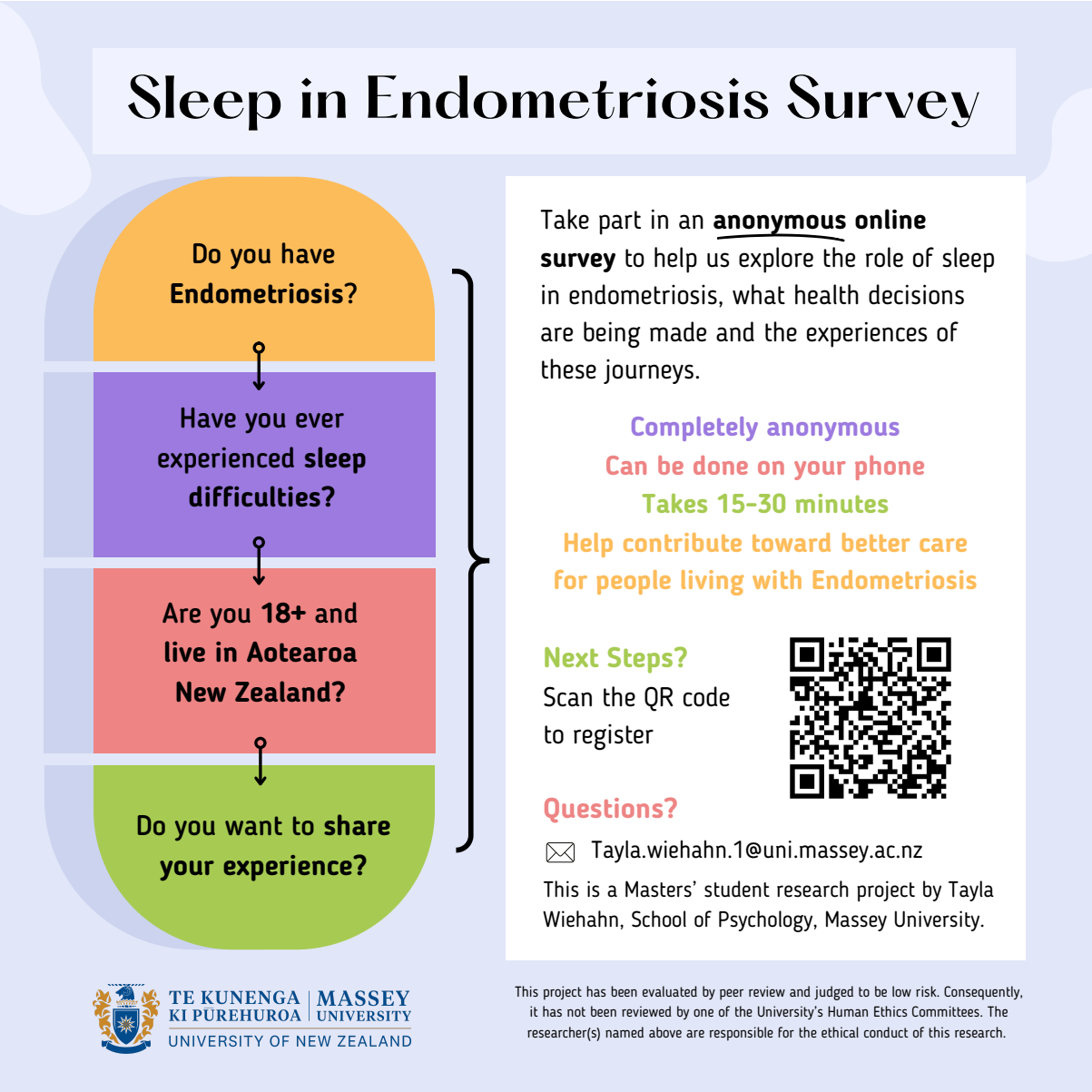

Appendix B

Information Sheet and Digital Survey

Block 1: Information Sheet

Sleep and related health decisions in New Zealand women with endometriosis.

Information Sheet

Thank you for your interest in this research. We invite you to complete an anonymous online survey about the health decisions you have made to support your sleep. The study is being conducted by Tayla Wiehahn as part of completing her Master of Arts (Psychology) degree through Massey University. She is supervised by researchers in the Sleep/Wake Research Centre (School of Health Sciences) and the School of Psychology at Massey University. This information sheet will help you decide if you would like to take part.

What is this study about?
Endometriosis is a chronic condition affecting one in eight people. An often-overlooked aspect of living with this condition is the impact on sleep. In Aotearoa New Zealand, there is currently no research exploring how people with endometriosis manage their sleep issues, what healthcare decisions they make, and how supported they feel throughout this journey. This study aims to explore the sleep experiences of people living with endometriosis and the healthcare decisions made to address any sleep difficulties.

Who will participate?
To participate in this study, you will need to:

- Be aged 18 years or older
- Be living in Aotearoa New Zealand
- Have received a diagnosis of endometriosis from a clinician, such as a doctor or surgeon
- Not have had surgery for the diagnosis or excision of endometriosis in the past 8 weeks

- Not be pregnant
- Have had or are currently experiencing difficulties with your sleep.

What you will be asked to do:
You are invited to complete an anonymous online survey that asks about your current experiences of endometriosis and sleep, and your quality of life. You will also be asked about the health-related decisions you have made to support your sleep, including anything you have tried, what health providers you have seen, what treatment or support you have received and how effective it was. We expect that the survey will take 15-30 minutes to complete.

To thank you for your time, you will be invited to enter a prize draw to receive one of 10 $50 Prezee e-vouchers. If you wish to go into the draw, you will need to provide your name and email address at the end of the survey.

How will your data be looked after?
All information you provide will be kept anonymous. You will not be able to be identified from your responses. If you provide contact details for the prize draw, these will be kept confidential and separate from your survey responses. All contact details will be deleted after the prize draw.
Your survey responses will only be used for research purposes and will be stored securely on password-protected computers in password-protected files, which will be available only to the research team. The study data will be stored electronically at the Sleep/Wake Research Centre, Massey University, for a period of 10 years, after which time it will be archived so it may be used in future research focusing on sleep in those with endometriosis.

What are my rights?
Completion of the survey implies consent. You are under no obligation to participate in this study. As the survey is anonymous and we cannot identify you, any responses you provide cannot

be deleted.
If you decide to participate, you have the right to:

- Contact the research team at any time to ask any questions about the study.
- Decline to answer any question or stop completing the survey by closing the browser window.
- Provide information on the understanding that no identifying details will be used.
- Request a summary of the project findings from the research team when the study is concluded.

What are the benefits and risks of participating?
This study is for research purposes. The findings will contribute to better knowledge and care for people living with endometriosis who struggle with their sleep.
There are no major risks anticipated in taking part, but if you would like further support for your sleep or endometriosis, you may wish to access the following resources and services.

Sleep Health Foundation *www.sleephealthfoundation.org.au*
Endometriosis New Zealand *www.nzendo.org.nz/helping-you*
Healthline New Zealand *www.healthy.org.nz*

Where can the results of this study be found?
Summaries of the research findings will be made publicly available on the Sleep/Wake Research Centre website (www.sleepwake.ac.nz) and social media channels. You may also request a summary of the findings from the research team (see contact information below).

Project Contacts:
Please feel free to contact the researchers listed below if you have any questions about the study.

Student Researcher:
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Primary Supervisor:
Dr. Karyn O'Keeffe, PhD
Sleep/Wake Research Centre, School of Health Sciences
Massey University
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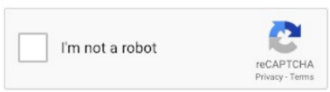
Who has approved this study?
This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact the Director, Research Ethics, email humanethics@massey.ac.nz.

Participant Consent:
Completing and returning this questionnaire implies consent. You have the right to decline to answer any question. I confirm that I have read and understood the information sheet for this study and consent to the collection of my responses. (Please select YES if you wish to proceed).

○ Yes ○ No

Please tick the box to indicate you're a real person.



Block 2: SCREENING Country

The following questions ask general questions about you and your endometriosis diagnosis.

Please note: Once you submit your responses or exit this survey, you will not be able to return or re-enter the study.

Where do you live?

Block 2: SCREENING Age

How old are you?

Block 2: SCREENING Dx of Endometriosis

Have you been diagnosed with endometriosis by a health professional?

- ○ Yes
- ○ No

Block 2: SCREENING Pregnant

Are you currently pregnant?

- ○ Yes
- ○ No

Block 2: SCREENING Surgery in past 8 weeks

Have you had any surgery for diagnosis or excision of endometriosis tissue in the last 8 weeks?

- ○ Yes
- ○ No

Block 2: SCREENING Sleep difficulties

Do you currently have, or have you ever had, difficulties with your sleep?

- ○ Yes
- ○ No

Block 3: Demographic questions

The following questions ask about you and your health.

Which ethnic group(s) do you belong to? Select the option or options that apply to you.

- ☐ New Zealand European
- ☐ Māori
- ☐ Samoan
- ☐ Cook Island Maori
- ☐ Tongan
- ☐ Niuean
- ☐ Chinese
- ☐ Indian
- ☐ _____ Other (Please state, e.g., Dutch, Japanese, Tokelauan):
- ☐ I'd prefer not to answer

Are you currently menopausal? Please tick one option that best describes you.

- ○ No, I am pre-menopausal (I still get menstrual periods, and don't have menopausal symptoms)
- ○ I have peri-menopausal symptoms (e.g., hot flushes, sleep changes, mood shifts), and still get menstrual periods
- ○ I am post-menopausal (it has been more than 12 months since my last menstrual period, and I may or may not still have symptoms)
- ○ I am not sure.

Do you have any of the following health conditions? (Select all that apply.)

- ☐ Sleep condition/s (e.g., insomnia, sleep apnoea, restless legs syndrome)
- ☐ Mental health condition/s (e.g., depression, anxiety).
- ☐ Other hormone condition/s (e.g., premenstrual syndrome, PCOS, PMDD)
- ☐ Other chronic pain condition/s (e.g., fibromyalgia, painful bladder syndrome, arthritis, headaches or migraines)
- ☐ Neurological condition/s (e.g., stroke, epilepsy, Parkinson's disease, chronic fatigue syndrome)
- ☐ Heart condition/s (e.g., high blood pressure, heart disease, high cholesterol)
- ☐ Metabolic condition/s (e.g., diabetes, thyroid disease, Addison's disease)
- ☐ Neurodevelopmental conditions/s (e.g., ADHD, autism spectrum disorder)
- ☐ Gastrointestinal condition/s (e.g., irritable bowel syndrome, reflux)
- ☐ Other (please specify) _____
- ☐ No, I do not have any of these health conditions

Block 4: Endometriosis Symptoms and Diagnosis

The following questions ask about your diagnosis and current symptoms of endometriosis.

Which of these symptoms of endometriosis do you currently experience? (Please select all that apply.)

- ☐ Painful periods
- ☐ Pelvic pain
- ☐ Irregular menstrual cycles
- ☐ Heavy periods
- ☐ Mood swings related to your periods

- [ ] Digestive issues related to your periods (e.g., abdominal bloating, irregular bowel movements, abdominal pain, food sensitivities)
- [ ] Other. Please specify
- [ ] I do not currently experience any symptoms

How would you describe the severity of your current symptoms of endometriosis?

- ○ Not at all
- ○ Slight
- ○ Moderately
- ○ Very
- ○ Extreme

How many years ago did your symptoms of endometriosis first begin?

- ○ Less than one year ago
- ○ 1-2 years ago
- ○ 3-5 years ago
- ○ 6-10 years ago
- ○ 11-20 years ago
- ○ 21-30 years ago
- ○ More than 30 years ago

Are you currently taking any medication/s to help manage your symptoms of endometriosis?

- ○ Yes
- ○ No

What medication/s do you currently take to help manage your symptoms of endometriosis? Select all that apply.

- [ ] Pain relief medication (e.g., Paracetamol, Ibuprofen, Naproxen, Diclofenac)
- [ ] Strong pain relief medication (e.g., Codeine, Tramadol, Morphine)
- [ ] Hormonal contraception (e.g., the oral contraceptive pill, the mini pill, Depo Provera injection, Mirena IUD, Zoladex)

☐ Antidepressant medication (e.g., Sertraline, fluoxetine, escitalopram, amitriptyline, nortriptyline)

☐ _____ Other. Please specify

Block 3: Quality of Life Questions

Thank you.
The following questions ask about your general well-being whilst living with endometriosis.

During the past 4 weeks, how often because of endometriosis have you....

	Never	Rarely	Sometimes	Often	Always
Found it difficult to walk because of pain?	○	○	○	○	○

	Never	Rarely	Sometimes	Often	Always
Felt as though your symptoms are ruling your life?	○	○	○	○	○
Had mood swings?	○	○	○	○	○
Felt others do not understand what you are going through?	○	○	○	○	○
Felt your appearance has been affected?	○	○	○	○	○

Block 6: Sleep Disturbance Questions

Thank you.
The following questions ask about your sleep.

How many hours of sleep in do you usually get in 24 hours?

hours

minutes

In the past 7 days…

	Not at all	A little bit	Somewhat	Quite a bit	Very much
My sleep was restless	○	○	○	○	○
I was satisfied with my sleep	○	○	○	○	○
My sleep was refreshing	○	○	○	○	○
I had difficulty falling asleep	○	○	○	○	○

In the past 7 days…

	Never	Rarely	Sometimes	Often	Always
I had trouble staying asleep	○	○	○	○	○
I had trouble sleeping	○	○	○	○	○
I got enough sleep	○	○	○	○	○

In the past 7 days, my sleep quality was….

- ○ Very poor
- ○ Poor
- ○ Fair
- ○ Good
- ○ Very good

How many years ago did you **first** experience difficulties with your sleep?

- ○ Less than one year ago
- ○ 1-2 years ago

- ○ 3-5 years ago
- ○ 6-10 years ago
- ○ 11-20 years ago
- ○ 21-30 years ago
- ○ More than 30 years ago

We are interested in learning about the healthcare decisions you have made to support your sleep, including any healthcare providers you may have discussed sleep concerns with. Consider any health providers you have discussed both current and previous sleep concerns with.

Have you ever discussed your sleep concerns with a healthcare provider?

- ○ Yes
- ○ No

Block 7: Healthcare providers consulted

Which healthcare provider/s have you seen for your sleep concerns? (Please select all that apply.)

- ☐ General practitioner
- ☐ Other primary health provider (e.g., nurse, pharmacist)
- ☐ Gynaecologist
- ☐ Other medical specialist (e.g., pain specialist/neurologist, sleep specialist)
- ☐ Mental health professional (e.g., psychologist, counsellor)
- ☐ Natural health professional (e.g., naturopath, Traditional Chinese Medicine practitioner, Rongoā Māori practitioner)
- ☐ Body therapist (e.g., massage therapist, acupuncturist, chiropractor)
- ☐ Dietician
- ☐ _____ Other. Please specify

In what order did you see the following health care providers for your sleep concerns?

- General practitioner
- Other primary health provider (e.g., nurse, pharmacist)
- Gynaecologist
- Other medical specialist (e.g., pain specialist/neurologist, sleep specialist)
- Mental health professional (e.g., psychologist, counsellor)
- Natural health professional (e.g., naturopath, Traditional Chinese Medicine practitioner, Rongoā Māori practitioner)
- Body therapist (e.g., massage therapist, acupuncturist, chiropractor)
- Dietician
- Other. Please specify

The next questions ask about each healthcare provider you have seen for your sleep concerns.

Block 9: LOOPING BLOCK

When did you first visit your **${lm://Field/1}** for your sleep concerns?

- ◯ Less than one year ago
- ◯ 1-2 years ago
- ◯ 3-5 years ago
- ◯ 6-10 years ago
- ◯ More than 10 years ago
- ◯ I don't remember

How many visits in total did you make to your **${lm://Field/1}** for your sleep concerns?

- ◯ 1 2 3 4 5-9 More than 10 I don't remember
- ◯
- ◯
- ◯
- ◯

How comfortable were you talking to your **${lm://Field/1}** about your sleep-related concerns?

- ◯ Extremely uncomfortable
- ◯ Somewhat uncomfortable
- ◯ Neither comfortable nor uncomfortable
- ◯ Somewhat comfortable
- ◯ Extremely comfortable

When visiting your **${lm://Field/1}** for your sleep concerns, what support were you given? (Select all that apply):

- ☐ Sleep Medication (e.g., Xanax, Lorazepam, Diazepam, Zopiclone)
- ☐ Melatonin
- ☐ Anti-psychotic medication (e.g., Quetiapine)
- ☐ Antidepressant medication (e.g., Fluoxetine, Sertraline, Citalopram, Nortriptyline)
- ☐ Medical Cannabis products (e.g., CBD oil/cream/tea, cannabis flower)
- ☐ Natural Medicine (e.g., herbal medicine, nutritional supplements, aromatherapy, herbal tea)
- ☐ Lifestyle management tools (e.g., exercise, sleep-hygiene techniques, self-care)
- ☐ Diet advice (e.g., removing caffeine, a nutrition plan)
- ☐ Psychotherapy (e.g., cognitive behavioural therapy (CBT), counselling)
- ☐ Manual manipulation (e.g., chiropractic adjustments, massage)
- ☐ Referral to another health care provider
- ☐ _____ Other. Please specify
- ☐ I was not given any support

How effective was the treatment from your **${lm://Field/1}** for your sleep concerns?

- ○ Not effective at all
- ○ Slightly effective
- ○ Moderately effective
- ○ Very effective
- ○ Extremely effective

How satisfied were you with the care you received from your **${lm://Field/1}** for your sleep concerns?

- ○ Extremely dissatisfied
- ○ Somewhat dissatisfied
- ○ Neither satisfied nor dissatisfied
- ○ Somewhat satisfied
- ○ Extremely satisfied

Block 8: Barriers

The following questions ask about barriers you may have faced when accessing healthcare for your sleep concerns.

What has stopped you from speaking to a healthcare provider about your sleep concerns?

- ☐ The cost was too high
- ☐ I worried I would be asked something I didn't want to answer
- ☐ I had concerns about side effects/adverse reactions to treatment
- ☐ I didn't think that my sleep concerns were serious enough
- ☐ I tried managing it on my own first
- ☐ I had negative experiences with healthcare providers in the past
- ☐ I didn't think healthcare providers would help
- ☐ I didn't know who to consult with
- ☐ I didn't have time to make an appointment
- ☐ I felt embarrassed or ashamed about seeking help for my sleep

☐ Other. Please specify

Block 10: Other health decisions

Thank you. The next questions ask about strategies you have used to support your sleep, without the input of a health provider.

What self-help strategies have you used to improve your sleep on your own, without seeing a healthcare provider? (Select all that apply.)

☐ Natural products (nutritional supplements like Magnesium or L-Theanine, or herbal medicine like herbal tea, Sleep Drops, Rescue Remedy, Lavender essential oil)
☐ Sleep trackers (e.g., a smart watch) or sleep apps
☐ Smoking or vaping
☐ Alcohol
☐ Exercise/exertion levels

☐ Yoga or Tai Chi
☐ Self-care practices (e.g., adjusting my schedule, avoiding screens at night, and/or practising good sleep habits)
☐ Diet (e.g., reducing caffeine, avoiding certain foods)
☐ Other (please specify):
☐ I have not used any self-help strategies to improve sleep

My self-help strategies have been effective in managing my sleep concerns.

Strongly disagree
Somewhat disagree
Neither agree nor disagree
Somewhat agree
Strongly agree

Block 11: Qualitative Questions

Thank you. There are just two questions left.

We are interested in your personal experience of sleep-related healthcare. Think carefully about these questions, and answer as in-depth as you'd like.

If there was one thing that you wish could be different about your healthcare experience for your sleep issues, what would it be?

Is there anything else you'd like to share about your experience seeking help for sleep?

Block 12: Contact details for prize draw OR summary of results

You have reached the end of the survey.

As a thank you for taking the time to share your experiences, we invite you to enter a prize draw for one of 10 $50 Prezzee e-vouchers.

You can also choose to receive a summary of the research findings once the study is complete.

To do this, you will be redirected to a separate form to share contact details. These will be kept separate from your survey responses.

Select 'Yes' if you wish to enter the prize draw and/or receive a summary of the findings .

- ○ Yes
- ○ No

Appendix C

Low Risk Notification

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

10/06/2025

Dear: Tayla Wiehahn

Re: Low Risk Notification - 4000030712 - Sleep and related healthcare decisions and experiences for people living with endometriosis in Aotearoa New Zealand.

Thank you for submitting a low risk notification for your research/teaching/evaluation.

This email is to acknowledge receipt of the low risk notification and to inform you that the details of your project have been recorded in our database for inclusion in the annual reports to the Health Research Council Ethics Committee (HRCEC) and the Massey University Research Committee (URC).

You may proceed with your research, though it is advisable to provide a couple of weeks before commencing, as all low risk notifications are checked for completeness and clarity by a Research Ethics Advisor. You may be contacted if your application is incomplete and/or further clarification is required.

The low risk notification for this project is valid for a maximum of three years.

Please notify me if situations subsequently occur which cause you to reconsider your initial ethical analysis.

If a sponsoring organisation, funding authority (e.g., the Health Research Council) or a journal require evidence of ethical approval from a Human Ethics Committee (with an approval number), you need to complete a full Massey University Human Ethics application to be reviewed and approved by one of our Human Ethics Committees. Applications must be submitted and approved prior to the commencement of the research.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact the Research Ethics Office, email humanethics@massey.ac.nz. "

Please include the following statement on all public documents (e.g., information sheet, consent form) related to your project:

> ***This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.***
>
> ***If you have any concerns about the ethical conduct of this research that you want to raise with someone other than the researcher(s), please contact Massey University Human Ethics by email: humanethics@massey.ac.nz.***

I wish you all the best in your research, teaching or evaluation activities and appreciate your thoughtful consideration of ethics principles and practices.

Ngā mihi nui,

Professor Tracy Riley
Acting Chair, Research Ethics Chair's Committee

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 951 6840
E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

Appendix D

Advertising Strategy Supplementary Material

This supplementary material outlines the advertising strategy used to disseminate the survey poster to relevant professional networks, community groups, and on social media, to recruit participants.

First, an appealing advertisement was designed on Canva (see Appendix A). This advert was initially advertised on social media platforms and web pages of the supervisory teams' existing professional network, the Sleep/Wake Research Centre (SW/RC). Paid online advertisement was used for 14 days on Instagram, using keywords such as "wellbeing", "sleep" and "lifestyle habits" to help boost survey visibility and increase survey responses. The survey advert was also posted on *Massey University Post-graduate Research Facebook* group, and community Facebook pages, including that of *Fertility NZ*, *Endometriosis, Adenomyosis, and Pelvic Pain NZ support*.

Simultaneously, I contacted other related professional networks via e-mail, inviting recipients to share the survey on social media and webpages. The e-mail template used to contact relevant professional networks is as below:

> "Kia ora,
> I hope this email finds you well.
> My name is Tayla Wiehahn. I am a Master of Arts (Psychology) student at Massey University, under the supervision of Dr. Karyn O'Keeffe from the Sleep/Wake Research Centre. I am conducting an anonymous online survey exploring the sleep experiences of people living with endometriosis, the healthcare decisions they make to address any sleep difficulties, and their experience through this process. We hope this research will help inform better knowledge and care for people living with endometriosis who struggle with their sleep in New Zealand.
> I've noticed that you share research projects on your website and on social media pages, and I wonder if you would be willing to distribute the attached

advertisement to your community. If you're happy to do so, I would really appreciate your support in reaching people who may be eligible to participate. Please let me know if this would be possible and if there are any guidelines we should follow.

If you would like any additional details about the study or have any questions, please don't hesitate to contact me at Tayla.Wiehahn.1@uni.massey.ac.nz or my research supervisor, Dr. Karyn O'Keeffe, PhD., at K.M.OKeeffe@massey.ac.nz.

Thank you in advance for your consideration. I look forward to your response.

Nga mihi,

Tayla Wiehahn"

As a result, the survey was advertised on both the *Menstrual Health Research Group* and the *Women's Health Action* social media and web pages. Each of these online posts were shared on other online pages and e-mail chains, helping distribute this survey to groups who may not have been reached otherwise.

Additionally, posters of the survey advertisement were printed as a flyer and distributed around the Massey University Otēha campus.

Because of the multiple avenues of dissemination, it was unclear how many of the survey responses were attributed to which platform. Together, these advertisement strategies helped share the survey diverse range of potential survey participants.

Appendix E

Reflexive Thematic Analysis Supplementary Material

Familiarisation Notes and Reflections – 10 November 2025

The familiarisation process started in an Excel Spreadsheet, where all responses were exported onto two sheets – one for qualitative question 1 and one for qualitative question 2. Responses to both questions were capturing what could have been improved; therefore, they were analysed together as a single large group.

I expected the responses might be negatively toned, given the extensive literature showing a negative outlook on public healthcare, and by how the qualitative questions were framed. But I wasn't expecting to feel so connected to a lot of them.

The process followed was first reading the responses without taking any notes. This took a while as there were about 550 responses, varying in length. The second read-through was broken up over a few days.

Initial thoughts:

- I'm hearing a lot of "it's just…x y z" - frustration
- Personal blaming
- Desire to be taken seriously
- recognition of it being linked together
- 'Palmed off' to medication isn't desired
- generic advice vs personal advice
- I wish… statements
- shaming about weight/personal fault

My Reflections During the Familiarisation Process

- Lots of frustration and emotions by the participants and by me. Feeling of injustice toward women.

- Lots of accounts talking about endometriosis experience in general, not separating sleep as independent.
- Such a variety of medications mentioned
- Lots of feeling that medications are "pushed" onto them by doctors. This is surprising.
- Surprising interest in natural therapies – I was expecting negative accounts of supplement use. Surprised at openness. However, this seems to be inspired by first experiencing frustration and hopelessness via other care methods.
- Overall, people are feeling comfortable, satisfied, empowered and are a part of their care
- People are aware of their own bodies, symptoms, health. Strong opinions on self.
- Element of luck, a certain way to act with doctors and in life (when living with sleep disturbances)
- Lots of strong negative emotions toward healthcare encounters, but little talk of expressing these emotions in the healthcare encounter – as if this survey is a place to let it all out
- Theres a sense of participants feeling like they've been burned before by healthcare professionals.
- Overall, responses aligned with my expectations but I'm surprised at how people express openness and gratitude toward natural alternative therapies.
- Theres a divide in accounts of feelings toward GPs, specifically – "trust GP" camp (lucky to have a good doc, doctors can only do so much in the little amount of time they have), "scared of GP" (sheepish, shy to bring up sleep issues, or to advocate), "mistrust in GP" (nothing works, doctors suck, healthcare sucks, not worth the discussion, other health practitioners are better).

Coding Notes and Reflections – 06 Jan 2026

In the Excel sheet, I used the columns next to each response to place the codes. I placed 1 code per cell. I wrote semantic codes only for the first 2 rounds, because I

wanted clear descriptions of what was being said, and it was recommended to do so for novice reflexive TA researchers. About halfway through the initial round of coding, I noticed a few similar codes popping up frequently because Excel had saved them and was auto-suggesting them as I started typing. These were “lack of HP inquiry”, “desire for GP inquiry”, “medication is superficial”, and “desire to be heard”. I then started writing these frequently occurring codes down on a separate document, as the start of the formation of my ‘Master Code’ list. On the 3rd round of coding, I then placed latent codes in brackets to keep them distinct from the semantic/descriptive ones. Notes during this process were documented:

Emotional tone of the journey experiences?

- Anger
- Frustration (with conflicting advice)
- Feeling disregarded
- Minimized
- “Dream of a magic pill” hopes
- Irritation
- Disheartened (‘been burned before’ vibes)
- Discomfort at GPs

What keeps recurring?

- Meds are superficial advice
- Worry of medication-seeking stigma
- Dismissal by GP
- Lack of GP inquiry of sleep issues
- Bad side effects from medications
- Mixed feelings about medications – some helpful, some hate, almost all are still hesitant despite being on/off meds
- “lucky” for a Healthcare professional to have acknowledged sleep

Central feelings?

- Desire for more effective care

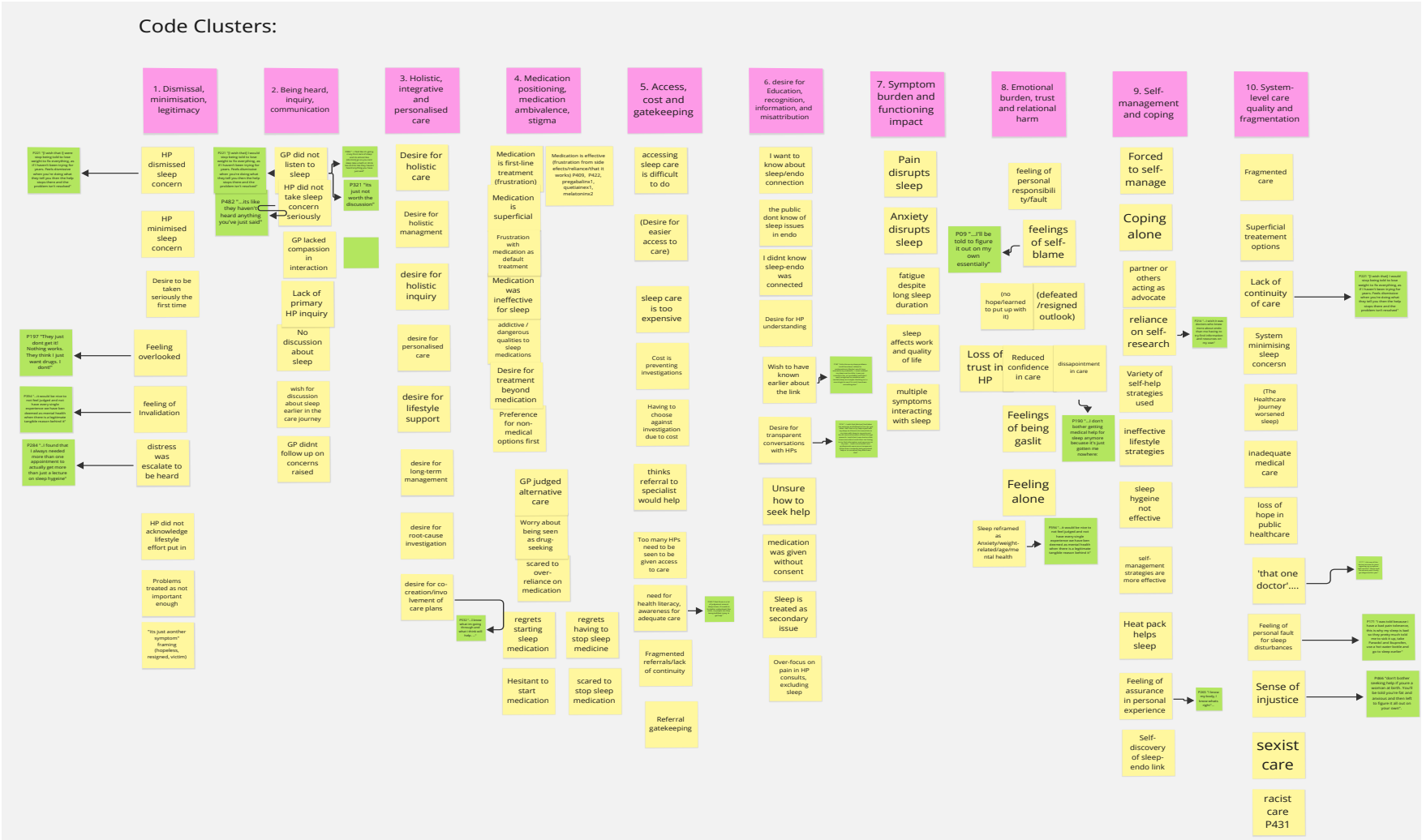
- Desire for more holistic care (interdisciplinary approach, natural supplements, testing).
- Cry for help
- Forced reliance on healthcare to help, but still inadequate
- Fear of HP/care/system,
- Desire for informed choices
- Wish for more inquiry now and in the past, as if it would have changed outcomes
- Sleep is always treated in relation to anxiety/weight/mental health/age/menopause

Some participants spoke of the research itself and how they were grateful for research like this, which made me feel like this was important research. I didn't analyse these for theme development as they were too meta and not aligned with research aims.

From my codes, I transferred my master codes from the separate document to Miro, where I dragged and dropped them under headings. These became my rough code clusters. I then went back through my Excel sheet to copy and paste any other codes that fit within these code cluster headings. I initially had 10 clusters of codes and attached a few key quotes that related to them to each of the relevant codes. See my Miro.com board (Figure E1) for code clusters.

Figure E 1

Code Clusters



Theme Development and Reflections - 20 Jan 2026

- A central theme in my reflexive TA was trust/mistrust. A lot of strong opinions for negative experiences relating to trust. So, I re-examined the coded data to see any proof of other opinions to avoid biasing the dataset and give a voice to everyone.
- The theme is not only about trust, as the supervisory team pointed out. Some trust their Dr but are still not having effective treatment…. What about those?

Initial theme development discussions lingered on the idea of trust vs mistrust in accounts of the experience of sleep-related healthcare journeys. Once discussed and brainstormed further, 'trust' was discovered to be a misrepresentation. 'Suspiciousness', 'ambivalence', 'misalignment' were more appropriate words that represented the codes from the data. Corresponding reflexive notes during theme development process are as below:

Preconceived ideas of what sleep care SHOULD be like:

- Matched the level of perceived importance of sleep
- Empathy, genuine concern, time to listen to full breadth of lived experience
- An honest conversation about the scope of sleep care in the primary care setting, and a referral to a sleep study or specialist
- A holistic treatment plan – supplements, Rongōa Māori, medicinal cannabis, mental health support, a "sleep study" or "sleep tests".
- An easily accessible melatonin prescription that is affordable.
- Leave with no clear pathway toward resolution, and less hope in the system's ability to adequately care for sleep

Preconceived ideas of what sleep care WILL be like:

- A dry "lecture" on sleep hygiene practice that you've already tried

- A dismissive, short conversation about how sleep is only ever an issue due to mental health concerns
- Unwarranted prescription of psychiatric medication
- Be told to lose weight, rest more, and that there isn't much that can be done
- Leave feeling like it's your fault, with no resolution.

Key concepts developed from my interpretation of the data were depicted in drawings by me, which eventually created a clear idea of what themes were centered around. See Figure E2.

The final themes were refined and brainstormed. See Figure E3 and Figure E4. The finalised themes revolved around two concepts: 1) A mismatched legitimacy between lived experience and clinical importance of sleep, and 2) The limits of sleep care, which included the downstream effects (frustration, responsibility shifting toward the individual, disengagement or self-management).

Figure E 2

Theme Development Ideas Mind Map

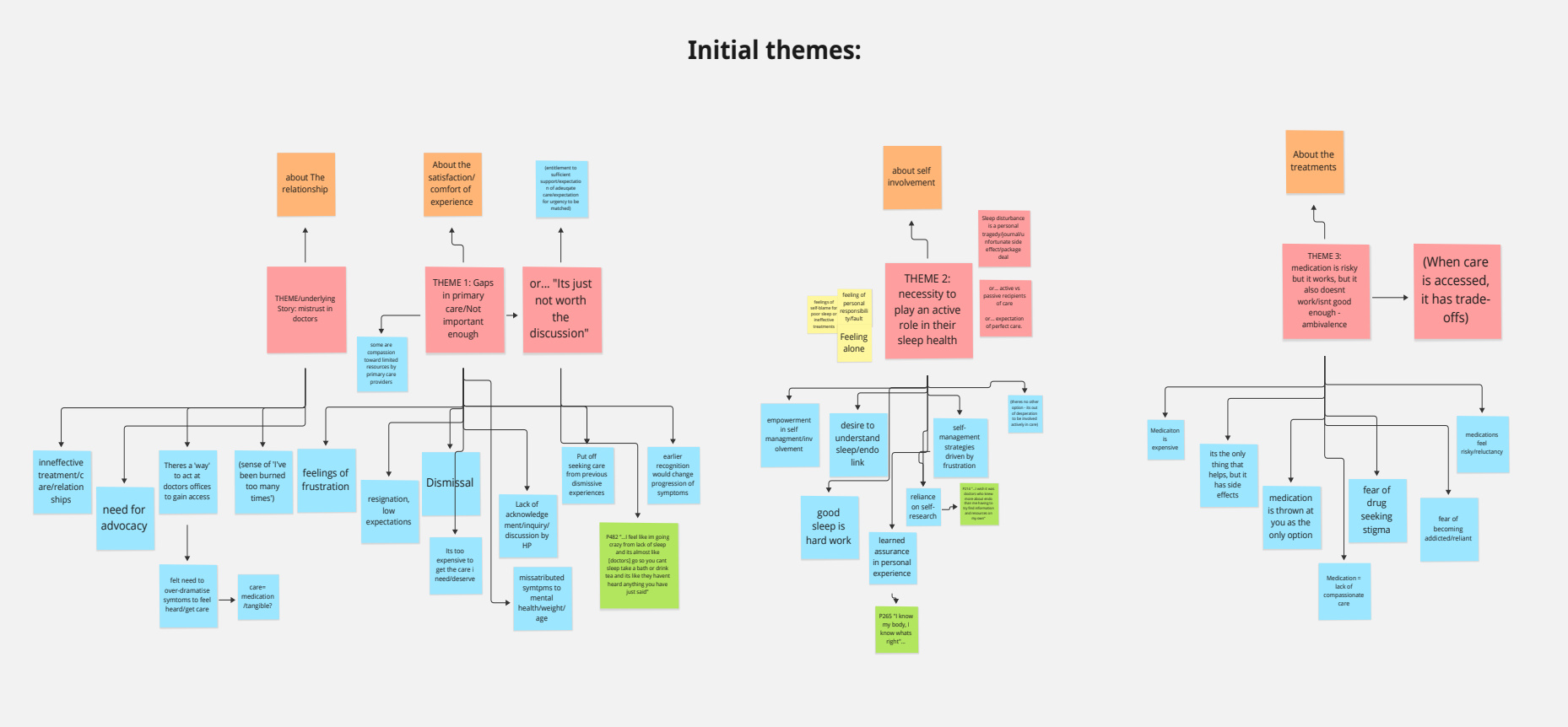


Figure E 3

Key Ideas to Include in The Finalised Themes (Depicted)

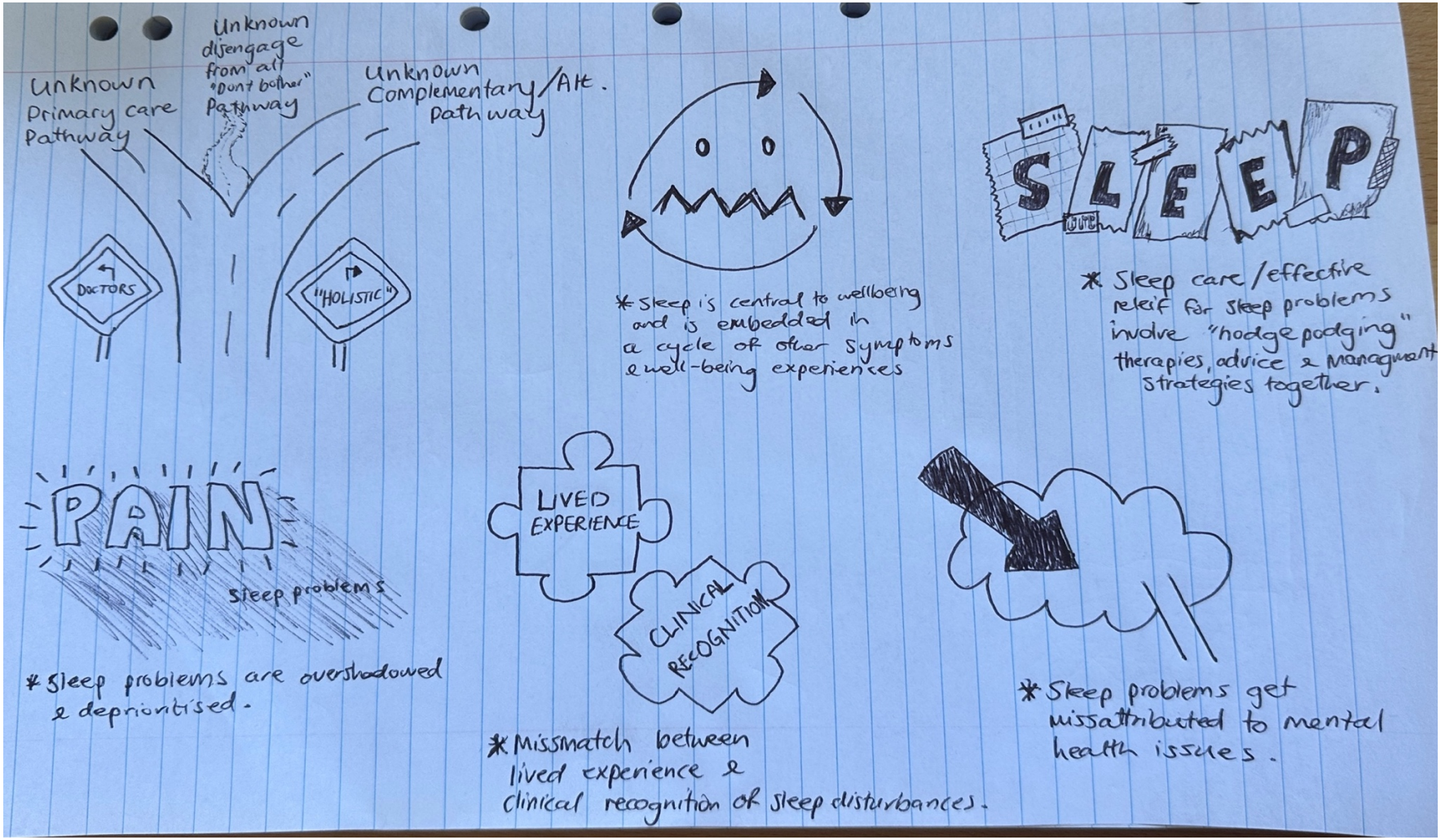


Figure E 4

Refined Theme Development Mind Map