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**The Impact of Endometriosis on Female Athletes' Lives and Wellbeing: A Qualitative  
Study**

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## **Abstract**

Endometriosis is a disease characterised by chronic pelvic pain and has a prevalence of around 8% in athletes. This study aimed to explore the experiences of athletes with endometriosis and the impact on their lives. Endometriosis is known to be incredibly burdensome for women, but this has not yet been explored specifically in athletes. Nine (9) women with a surgical diagnosis of endometriosis participated in semi-structured interviews, which were recorded and transcribed. Critical realism and feminist theory informed the approach. This data was analysed using reflexive thematic analysis, and four themes were developed. Firstly, Theme One: “A Cloud Over You” The Burden of Endometriosis, details the burden of endometriosis on athletes and how chronic pain impacted almost every area of their lives, including training, performance, and mental health. Theme Two: “How was your Holiday?” Experiences of Invalidation and Minimisation describes the attitudes and lack of empathy that participants were subjected to from healthcare practitioners (HCP), their coaches and support staff, and for some, their social supports. Theme Three: Recognising “Maybe This Isn’t Normal” Advocacy and Overcoming evaluates the time when each participant realised in some way that what they were experiencing was not normal, which caused them to seek more help. This theme also details the self-advocacy required to achieve substantial change. Finally, Theme Four: “Thank God I’ve Got an Answer” Misdiagnoses, Diagnoses and Treatments, describes the difficulties participants experienced in seeking help. This study illustrates not only the need for future research on athletes with endometriosis, but also for improved attitudes and awareness for those working with athletes.

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“Physical pain has no voice,

but when it,

at last,

finds a voice,

it begins to tell a story”

(Scarry, 1987, p. 3)

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## Chapter One: Introduction

This chapter gives a broad overview of endometriosis before concluding with the aims and objectives of this project. Endometriosis is a debilitating condition that affects one in nine people with uteruses<sup>1</sup> of reproductive age and about 8% of New Zealand's professional athletes (Heather et al., 2020). Although most research focuses on women, endometriosis affects all genders, including, in rare cases, men (Jabr & Mani, 2014). In this study, I will refer to people living with endometriosis as 'female' or 'women', as all my participants in the research study were women.

Endometriosis is medically defined as the existence of functioning stroma (connective tissue) and glands growing outside the endometrium-the lining of the uterus (Chopra, 2020). Endometriosis is often found on the fallopian tubes, bowel and surrounding areas, but it can also occur elsewhere in the body, even in the diaphragm or brain (Chopra, 2020). Even though endometriosis is a relatively common condition, it is under-reported, under-researched and under-diagnosed (Gao et al., 2006). Although benign, this estrogen-dependent inflammatory disease can cause chronic pelvic pain (CPP), multiple surgeries and infertility (Giudice & Kao, 2004; Sourial et al., 2014).

These physical symptoms additionally have a negative psychosocial impact on sufferers. Women with endometriosis have expressed feelings of shame, fear, depression and an overall burden (Young et al., 2019). Unfortunately, due to social stigma, women often stay silent on these issues, and many believe that this kind of suffering is an expected norm or just part of being a woman (Matías-González et al., 2021). Endometriosis has received more research attention in recent years, and increasingly, researchers have begun to conduct qualitative studies

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<sup>1</sup> All participants identified as cisgender women



to investigate the psychosocial impacts of the disease. Many researchers recognise how endometriosis impacts jobs, relationships, well-being, and quality of life (Gao et al., 2006; Moradi et al., 2014). However, research on athletes with this condition is rare. Currently only one case study specifically about an athlete with endometriosis exists from 2007 and no studies have contributed to this field since (Jones et al., 2007).

As endometriosis affects 8% or possibly more athletes (Heather et al., 2020), research is warranted on how this impacts their lives and sport. It is hoped that this project will identify how athletes are affected, identify areas for further research, and highlight implications for elite sporting bodies. Accordingly, this research aims to explore female athletes' experiences of living with endometriosis, focusing on the effects of endometriosis on their lives, wellbeing, and the impacts on their sport. It aims to contribute to understanding of the significant challenges that may be experienced by athletes with endometriosis. Existing research on the burden of endometriosis and the stress that sport can create supports the hypothesis that athletes with endometriosis may experience significant challenges. Endometriosis may affect critical parts of sport like relationships with staff and coaches, mental health, peak performance, training and even identity and self-worth. I hope that by partaking in my research and being given a platform to share their stories with the research world, participants have felt listened to.

### **Aims & Objectives**

The overarching research question is: how does endometriosis impact the lives and well-being of female athletes? The research aims and objectives of this project are:

1. To understand the symptoms, journey to diagnosis, and treatment experiences of female athletes with endometriosis.

2. To understand the impact of endometriosis on sporting lives, including selection and relationships.
3. To evaluate the effects of endometriosis on female athletes' wellbeing, mental health, and future aspirations.

This chapter has outlined the aims and objectives of the research project. Next, Chapter Two provides a review of existing literature, describing the history of endometriosis, the symptoms, prevalence, and possible cause. Following this, Chapter Three covers methods and methodology. The findings and discussion are then presented in Chapter Four before, finally, strengths, limitations and recommendations are provided in Chapter Five.

## **Chapter Two: Literature Review**

This chapter aims to outline the current research on how endometriosis affects athletes. As only one study was identified on this topic specifically, my review covers broader areas of how endometriosis affects the lives of women in general and covers the effects of pain on athletes. In this review, I weave together these research bodies to understand how endometriosis may affect female athletes.

Firstly, I cover the history, symptoms, prevalence, and aetiology of endometriosis before investigating diagnosis, related delays, and some treatments. Following this, I explore the toll and burden that endometriosis takes on women and the related impacts on functions like sleep and employment. I then consider how social support can be a protective factor and a burden for those with endometriosis. Finally, I provide a summary of this review and research directions.

### **History**

The key symptom of endometriosis, chronic pelvic pain (CPP), has been observed in women in medical settings for over 4,000 years; however, endometriosis was not diagnosed medically until 1860 by Karl von Rokitansky (Chopra, 2020). CPP has been observed through the ages and, for centuries, was viewed as a consequence of things like promiscuity, weakness or even madness (Nezhat et al., 2011). Due to these views, hysteria was a common diagnosis (Brosens & Benagiano, 2011). Despite being heavily discredited, hysteria still significantly influenced attitudes about women throughout the 20th century when women's medical experiences were trivialised (Nezhat et al., 2011). For example, Reese et al. (1996) noted that over half of women with CPP were found to have no biological cause for their pain and, without a diagnosis, were again viewed as hysterical or mentally unstable. Despite recent leaps in scientific research, this notion of hysteria still lingers to this day (Chopra, 2020).

## **Physical Symptoms**

The most common symptom of endometriosis is CPP, which can be debilitating (Jones et al., 2007). Pain is often accompanied by heavy bleeding, painful periods (dysmenorrhea), painful bowel movements or constipation (dyschezia), pain during or after sex (dyspareunia), a burning sensation when urinating (dysuria), fatigue, and infertility (Bulletti et al., 2010). A key symptom often missed in the literature is known colloquially as ‘endo belly,’ which is severe bloating or gastrointestinal issues (Ek et al., 2015). Symptoms, however, are not indicative of the severity of the disease. Some with only mild endometriosis may experience severe pain, and those with extensive lesions may be asymptomatic (Denny & Mann, 2007).

## **Prevalence**

In recent years, clinical studies have shown that endometriosis affects at least one in ten women of reproductive age, which makes it one of the most common diagnoses in women with pelvic pain (Viganò et al., 2004). However, research suggests that endometriosis may be significantly more common than is currently recognised (Peterson et al., 2013). In terms of the prevalence of endometriosis in athletes, there is little research available. However, Heather et al. (2020) recently found that 8% of New Zealand elite athlete participants had a diagnosis of endometriosis. Considering that athletes spend their careers trying to minimise and overcome pain and have a higher pain tolerance than non-athletes, this could mean that endometriosis is under-reported or under-diagnosed in athletes as well (Pettersen et al., 2020).

## **Aetiology**

Endometriosis has been described as an enigma, as the exact cause is unknown (Valle & Sciarra, 2003). There are, however, some known risk factors. Firstly, although no specific genes have been identified, the risk of endometriosis is three to seven times higher in women with a

first-degree relative with endometriosis (Nouri et al., 2010). Secondly, having a short cycle length and early age of menarche are risk factors (Shafrir et al., 2018). Various speculations have been made about the influence of lifestyle and nutrition, but no firm conclusions have been drawn, except that exercise can reduce risk, and smoking and alcohol increase risk (Chopra, 2020; Farland et al., 2017; Missmer et al., 2010). Lastly, although exercise has been suggested as a protective factor, leanness has been identified as a risk factor for endometriosis (Farland et al., 2017). As athletes are leaner than the general population yet partake in exercise (Riewald, 2008), these factors could potentially contradict one another. However, most studies exploring the impact of exercise have studied moderate exercise. Because of this, it is yet to be established whether higher loads of exercise, such as that required in professional sport, is still a protective factor or whether it has a different effect.

## **Diagnosis**

As previously noted, the history of diagnosing women as hysterical instead of having a biological problem still has an effect today, impacting delays to diagnosis and misdiagnoses for women with endometriosis. Diagnosing endometriosis is a complex and expensive task (Agarwal et al., 2019) Not only are symptom-only diagnoses unreliable due to endometriosis having many shared symptoms with other diseases and symptoms being masked due to contraception, but endometriosis also cannot be found via blood tests or most types of scans (Chopra, 2020). The gold standard for diagnosis is the analysis of a tissue biopsy performed during laparoscopic surgery (Bazot & Daraï, 2017). However, surgery is not always effective, and many with endometriosis continue to suffer following surgery or even require multiple surgeries.

Surgery is an expensive and time-consuming exercise that athletes may be unable to afford financially. They may also struggle to take time off from training and competition to

pursue a diagnosis. Recovery times from surgery are not reported in the literature, but likely vary widely depending on the invasiveness and extent of the surgery. This may also create uncertainty for athletes about whether they wish to commit to surgery.

The hesitancy of healthcare practitioners and patients to choose surgery, combined with the issue that other diseases can cause similar symptoms, contributes to misdiagnoses of endometriosis. Irritable bowel syndrome, interstitial cystitis, pelvic inflammatory disease and fibromyalgia are some of the typical incorrect diagnoses (Bulletti et al., 2010). Young et al. (2020) found that women had to advocate for themselves strongly and ‘be their own doctor’ just to be taken seriously and ensure a correct diagnosis (Young et al., 2020). Before this, the same researchers examined clinicians’ language with women and endometriosis. They found that they were constructed as hysterical if they did not present with a simple diagnosis (Young et al., 2019). Despite empirical evidence that endometriosis is a biological disease, health systems continue to be influenced by old-fashioned and outdated notions of hysteria. Women with endometriosis are often treated as though their suffering is a psychological issue rather than a physical one and suffer long waits for information. In contrast, their well-being and function, and psychological health are affected.

### **Diagnostic Delay**

To further complicate the experiences of women with endometriosis, there are many misconceptions surrounding women’s pain. These misinformed ideas can contribute to a delay in diagnosis, or a misdiagnosis, so much so that endometriosis is often labelled the missed disease (Overton & Park, 2010). Research in the 1990s showed that medical professionals dismissed or trivialised women’s symptoms and that women waited on average 7-10 years to receive a diagnosis (Hadfield et al., 1996). Unfortunately, more recent research shows that the average

delay until diagnosis is still 7-8 years, and in this time, women see, on average, seven physicians while experiencing unbearable physical and emotional stress (Chopra, 2020). When women are finally diagnosed, some report feeling relief, hope, a sense of community, and feeling seen (Fernley, 2021).

### **Healthcare Practitioners (HCP)**

In a discourse analysis of interviews with general practitioners and gynaecologists, Young et al. (2019) and Krebs and Schoenbauer (2020) observed that clinicians endorsed a biological model of medicine as having the authority of knowledge on women and their experiences. Women were constructed, in line with historical narratives, as hysterical, especially women who were perceived as difficult or with whom treatments were less effective. The clinician's expertise being used to dismiss the patient's experience is identified in other research as invalidation (Bontempo, 2021a, 2021b; Kool et al., 2013; Witkowski, 2017). Feelings of invalidation can lead to relationship breakdown between clinician and patient as sufferers feel as though they are not being taken seriously. In addition, this lack of support can tangibly affect patients in that it can contribute to delays in the diagnosis and treatment of endometriosis (Kundu et al., 2015). Other research has shown that women had limited faith in healthcare practitioners and had to battle to get a diagnosis and the care they deserved (Grogan et al., 2018).

In contrast, Fernley (2021) highlighted the influence of 'that one doctor' who finally helped patients to receive care. The study evaluated online accounts of eighty-nine women with endometriosis who completed a qualitative thematic analysis of online autobiographical accounts. Fernley (2021) found that women endured long, emotional, and painful journeys to receive a diagnosis and noted how one doctor made them feel heard, speaking of the sense of

relief with their diagnosis and transforming their experience. For participants, this experience of being believed made them feel supported.

## **Treatment**

Regarding treatment, some evidence-based options include pharmaceutical medications, surgery, and lifestyle factors. However, despite decades of research on endometriosis, many practitioners still advise women to pursue outdated treatments (Nezhat et al., 2011). One of these ‘treatments’ is pregnancy, which was offered as a treatment over 4,000 years ago (Chopra, 2020). In the 1920s, Sampson (1922) observed reduced endometriosis symptoms during pregnancy, and others declared that pregnancy was a cure (Beecham, 1949). In addition, the prevalence of women with endometriosis without children appeared to support this theory (Meigs, 1922). However, it was soon recognised that the relief some experienced during pregnancy was short-lived (Ueda et al., 2010). Despite efforts to ‘debunk’ this claim academically, the notion took hold in the medical community, and pregnancy continues to be suggested as a cure by modern doctors (Alimdjanovna, 2021; Vercellini, 2015).

These ancient treatments and cures stem from myths about endometriosis, such as it being a career women’s disease that could be solved by having children or that women are just being hysterical (Chopra, 2020). In reality, women of any vocation, including sport, may have endometriosis, a biological disease without a cure (Molloy, 2005). The continued promotion of outdated treatments suggests that myths are perpetuated by outdated misogynistic views, which contributes to the long, painful journeys that women with endometriosis experience (Chopra, 2020). Throughout history, healthcare practitioners (HCP) have connected endometriosis to women departing from social norms and expectations of being a woman, such as motherhood and marriage (Jones, 2015). For many, endometriosis is considered not only a physical problem



but a “cultural construction that informs beliefs about the relationship between women’s reproductive anatomy and their social roles” (Jones, 2015, p. 1083). Modern and effective treatments include pharmaceutical medications for pain relief and the prevention of menstruation, surgery, and diet, which are explored next (Chopra, 2020; Denny & Mann, 2007; Molloy, 2005).

As endometriosis is without a cure or long-term treatment, women often have no choice but to use pharmaceutical medications to manage pain. Non-steroidal anti-inflammatory medications, analgesics like paracetamol, derivatives of codeine or opiates, or hormonal drugs are common (Denny & Mann, 2007). Unfortunately, these drugs have detrimental side effects, including addiction to some medications. In a recent study, Chiuve et al. (2021) worryingly found that women with endometriosis were at four times more risk of chronic opioid use than women without endometriosis. The reliance on medication for treatment may present a particular challenge for athletes, who are strictly limited in the medication they are allowed to take (WADA, 2021a). In elite-level sports, WADA (World Anti-Doping Agency) strictly rules that no medication may be used if it has performance-enhancing effects. This means that athletes who suffer from endometriosis either cannot use any of the more potent pain killers or would have to apply to WADA for a TUE (therapeutic use exemption), which may or may not be granted depending on their circumstances (WADA, 2021b).

Additionally, it is pertinent to note that this issue may intersect with diagnostic troubles, whereby being granted a TUE is impeded by a lack of diagnostic clarity prior to having surgery. For many, using an intrauterine device (IUD) or contraceptive pill helps reduce menstrual symptoms and, in some cases, dampens new growth of endometriosis (Xu et al., 2021).

However, for some, the side effects of weight gain, acne, and mood swings mean choosing between the pain of endometriosis and enduring these unwanted effects (Chopra, 2020).

As mentioned earlier, for a correct diagnosis, surgery is necessary. During this surgery, if endometriosis is found, it is often treated during the same surgery (Molloy, 2005). Although common, ablation (lasering of endometriosis tissue) does not always provide relief for patients (Wright et al., 2005). Complete excision (physical removal) of endometriosis is the gold standard treatment, and recipients see more considerable reductions in pain and less return of growth (Healey et al., 2010). Excision surgery can also help to reduce work absences and performance losses and improve quality of life (Wullschleger et al., 2015). There is currently no research on the effectiveness of surgery on athletes with endometriosis; however, considering that surgery can have such positive effects in women generally, female athletes would likely experience similar improvements or relief after receiving surgery. However, Sourial et al. (2014) note that surgery does not provide universal relief. It is not fully known precisely why this is, but one theory is central sensitisation (He et al., 2010). Central sensitisation occurs when chronic pain has caused the descending pain pathways of the brain to be deeply reinforced over time (He et al., 2010). In simple terms, this creates a neural path where the brain has sent the pain signal so many times that even when the problem causing the pain has ceased, the pain continues. This means that even when the endometriosis is removed, this pathway remains in place and long outlives its usefulness. Considering that pain reduces performance (Martins et al., 2014), it could be devastating for an athlete to have surgery in the hope that their pain would decrease, only to find that their pain returns.

Receiving a correct diagnosis can give women with endometriosis a strong sense of relief (Denny, 2004). It may seem strange that upon being informed about having a life-long, incurable

disease, women feel relieved but having CPP without a known cause can be a psychologically challenging experience (Denny, 2004). Having the knowledge that there is something physically wrong, as opposed to the alternative of symptoms being seen as normal or trivial or being ‘crazy’ has been reported to be a relief, and a sense of validation can occur (Cole et al., 2021; Culley et al., 2013). Following these long and painful journeys to diagnosis and once finally receiving one, women can be met with feelings of relief. During these delays, Grogan et al. (2018) found that most women, within their sample of thirty-four women did not receive an accurate diagnosis immediately and waited for times between four months and 25 years for their diagnosis. Participants relayed the dismissal and invalidation described earlier from healthcare practitioners (HCP), and many said they felt frustrated, hopeless, or alone during the wait. Once they finally received a diagnosis, Grogan et al. (2018) observed that participants acknowledged a sense of relief. While relief may seem strange when being diagnosed with a lifelong, painful, and incurable disease, this feeling has been noted in other settings. When interviewing 28 women with a diagnosis of endometriosis, Ballard et al. (2006) found that women benefited from receiving their diagnosis as it provided validation and reassurance that the symptoms were not related to cancer and gave participants language to be able to communicate about their ailment. Overall, having surgery and navigating the issues around surgery can be an added burden.

## **Burden**

Myths, misdiagnoses, expensive and time-consuming treatments, diagnostic delays, and most certainly pain unsurprisingly create a significant burden on the quality of life (QoL) of women with endometriosis (Moradi et al., 2014). These difficulties take a toll on relationships with HCP, family, friends, and partners. When doctors trivialise women, it is no surprise that the family and friends of women with endometriosis often under-estimate the effects. A study by

Facchin et al. (2018) found that friends and family often mistook women's suffering as simply being in a bad mood. Feeling misunderstood not only by doctors but by the people you trust can make coping with endometriosis harder (Grogan et al., 2018). Athletes may find that their coaches, staff or even teammates misunderstand or minimise their condition in sport. This could create barriers between athletes.

Considering that most sports staff are male (Clarke et al., 2021) and that female athletes already feel uncomfortable talking about things like their menstrual cycle with staff (Findlay et al., 2020), athletes could be even less willing to discuss menstrual dysfunctions or pain. Additionally, athletes can heavily rely on their significant other for support (Kristiansen & Roberts, 2010); however, women with endometriosis often feel misunderstood even by their own partners (Moradi et al., 2014). Culley et al. (2013) found that pain during intercourse, fatigue, and infertility compounded with other symptoms and made women with endometriosis feel highly distressed. These issues could create additional stress for athletes who already have the pressure of training and competing on their shoulders. Athletes may feel there is nowhere to turn when those closest to them do not believe them.

### **Athlete Experiences of Pain**

The single study identified in this literature search specifically about athletes with endometriosis was a case study on a female volleyball player who presented with lower abdominal and pelvic pain (Jones et al., 2007). The participant was an intercollegiate volleyball player who noted pain and increasing symptoms after the ball contacted her, which was followed up by a physical evaluation at the hospital emergency room. Even though this athlete had many of the critical symptoms of endometriosis, she was incorrectly diagnosed with a urinary problem. She was subsequently diagnosed correctly following specialist gynaecology care and receiving

laparoscopic surgery. The participant then returned to play and experienced a similar incident followed by a hospital visit.

While this case study is likely the first to highlight an athlete's experience with endometriosis, the study is constrained by limited detail on the methods used. Firstly, it is unclear how the information in the study was attained and whether an ethical approval process was completed. Secondly, this study claims that endometriosis rarely affects participation in sport and that partaking in sport increases episodes of endometriosis. Neither of these claims are currently evidenced by research. Thirdly, the study gives limited information regarding the experience of the athlete. The study states that the athlete withdrew from volleyball and gave up her scholarship. Still, it is unclear whether this was due to her experiences of endometriosis or due to other reasons.

As I did not identify any other studies specific to athletes with endometriosis in my search, I expanded the search to investigate how athletes are affected by pain, how this impacts their experiences, and how endometriosis affects the lives of women in general. Whilst injuries have a myriad of differences to a chronic, cyclical condition like endometriosis, some parallels regarding pain can be drawn, and unlike endometriosis, the impacts of injuries have been well investigated in sport. Athletes have been known to suffer physical effects, practical implications, and psychological consequences of injuries. Some physical impacts include reduced sporting performance (Hainline et al., 2017), biomechanical abnormalities or overuse causing further injuries (Igolnikov et al., 2018), and reduced training volume (Von Rosen et al., 2018). Practical implications include loss of funding and non-selection (Fruchart et al., 2020). Additionally, mental effects such as burnout (Cresswell & Eklund, 2006), mood disturbances such as tension, anger, depression, low self-esteem (Smith, 1996), even post-traumatic stress disorder or other

trauma-related mental disorders have been shown to occur as a consequence of injury in sport (Aron et al., 2019).

While the physical impacts of sports injuries have been well researched, the effects of endometriosis on the body of an athlete are unknown. It is likely, however, that the physical effects of pain from endometriosis could have similar effects to injury pain in terms of reduced performance. While elite and high-level athletes have been shown to have increased pain tolerance compared to non-athletes (Pettersen et al., 2020), pain has been shown to severely hamper performance on complex sporting tasks (Brewer et al., 1990). This may put athletes with endometriosis in technical sports at a higher risk of being physically impacted by their pain. Additionally, acute pain in one body area can reduce the performance ability of other body areas that are not in pain (Deschamps et al., 2014). This may mean that even though a person living with endometriosis is experiencing lower back pain, for example, other muscle groups could be impacted. This could potentially lead to performance decrements in athletes who have endometriosis. In terms of practical implications, injuries can lead to the non-selection of athletes for competitions or even being part of a team. In sport, as not selecting an athlete due to injury is judged to be an acceptable practice (Fruchart et al., 2020), it could be the case that if athletes fail to perform due to chronic pain from endometriosis, this could cause deselection; however, this is yet to be established in the literature. As non-selection often goes hand in hand with a loss of funding, this could have lasting implications for athletes.

## **Mental Health**

As noted, injuries and chronic pain impact not only physical but mental health. Research has shown that athletes who experience multiple injuries are more likely to experience burnout (Grylls & Spittle, 2008). This may be because numerous injuries have cumulative effects. For

those with endometriosis with ongoing pain, cumulative stress from chronic pain could be a risk factor for burnout. In addition, mood disturbances such as tension, anger, depression and low self-esteem have been associated with athlete injuries (Smith, 1996). Not being able to participate due to the effects of injury can have devastating effects, causing athletes to feel devalued and worthless and can cause them to spiral into depression, eating disorders, or anxiety (Campbell et al., 2021). Injured athletes have also been shown to have lower self-esteem than other athletes (Smith & Milliner, 1994), and in some cases, the severity warrants clinical intervention (Leddy et al., 1994).

Recent qualitative research highlights these issues. Ross et al. (2020) used semi-structured interviews to investigate the experiences of injury of 13 young adults following a sport-related knee injury and analysed the data using inductive thematic analysis. The qualitative, open-ended nature of the research enabled the researchers to generate rich data about how athletes perceived their experiences. The researchers found that the experience of being injured negatively affected athletes: they did not feel they had adequate care, their decisions to continue in sport were affected, there were long-term effects on their well-being and that injury negatively affected their athletic identity.

Additionally, considering the potential mental health impacts of chronic pain may be particularly relevant both for athletes and those with endometriosis. Athletes with endometriosis could potentially be at greater risk of suicide. Professional sport is an occupational category identified in the USA as having one of the highest suicide rates (Timpka et al., 2021). Most athletes are also in the most high-risk age group for suicide (Peterson et al., 2018). Further, researchers in the UK have identified that around half of the 13,500 women they surveyed about

their experience with endometriosis had had suicidal thoughts (BBC, 2019). Given these worrying statistics, there is a need to understand how to support athletes with endometriosis.

Smith and Milliner (1994) explored the experiences of five athletes who survived suicide attempts and identified themes that may have contributed to their risk. These included factors like experiencing success before the injury, needing surgery as treatment, extended rehabilitation, and being deselected. These are all factors that athletes with endometriosis may experience because of CPP and having to engage in severe treatments like surgery. Many women with endometriosis have to take time off work, cancel social plans or even end relationships due to the debilitating impacts of CPP (Gao et al., 2006). While it has not been demonstrated in the literature, it is worth considering that this may similarly affect athletes, with implications on training, selection, funding, relationship, wellbeing, and many other areas.

These possibilities may also be present for athletes with endometriosis who may additionally experience impacts on their quality of life. They may need assistance with symptom management, information, resources and support from their staff and peers. However, while the temptation exists to draw assumptions from these studies, it is vital to acknowledge the nuanced differences between endometriosis and injury. Not only is the context of the pain markedly different, but also the effects of that pain on sport may be different for individuals and for broader contexts as injuries may present stable pain until healed, as opposed to the cyclic and incurable nature of endometriosis. In the same vein, there is the additional issue that injury research relies on the athlete first acknowledging the injury.

In sport, it is often implied that only mentally robust athletes would be competitive at the highest level, leaving no place for mental distress (Markser, 2011). Athletes with mental illness have been considered ‘failures in the system’ and have been kept out of public view, and



consequently, little academic research has taken place in this field (Markser, 2011). However, recently, research has found that the prevalence of mental disorders is similar in athletes to their peers (Beable et al., 2017; Xanthopoulos et al., 2020). Xanthopoulos et al. (2020) found that athletes experience similar mental health concerns to peers, such as depression, anxiety, suicidal ideation, substance abuse, and eating disorders. They also observed that athletes had additional pressures of managing high external pressures and expectations and aiming for optimal performance. In addition, the loss of personal autonomy from such an intense focus on sport can be an additional risk factor for mental health issues (Cresswell & Eklund, 2007).

Beable et al. (2017) used the Centre for Epidemiological Studies Depression Scale—Revised (CESD-R) to measure symptoms of depression in 187 New Zealand female athletes and found depressive symptoms to be prevalent. Beable et al. (2017) also found, using the Daily Hassles Questionnaire (DHQ), that individual stressors were more severe and frequent in athletes than in the general population. While the DHQ does not include pain directly, other research has identified pain as a daily stressor (Hannibal & Bishop, 2014). In addition, many factors measured on the DHQ could be relevant to pain, such as ‘not getting enough sleep’, ‘troubling thoughts about the future’ and ‘trouble relaxing’. Considering that daily hassles, which are common among athletes, can cause chronic stress and that daily stressors have also been shown to exacerbate symptoms of other chronic health conditions (Piazza et al., 2013), it is likely that the burden of endometriosis could compound the already present daily hassles in athlete participants.

### **Perceptions of Pain**

The culture in many sports reduces the likelihood that athletes will open up about their injuries and suffering. Qualitative researchers have investigated attitudes in sports and found common themes of nondisclosure of pain or related suffering, which prevented athletes from

sharing about their injuries (Cresswell & Eklund, 2006; Gustafsson et al., 2011). Due to these attitudes, athletes can go unnoticed and unsupported during their greatest psychological struggles post-injury (Gervis, Pickford, Hau, & Fruth, 2019). This may be partly due to the overarching view in sport that pain is perceived as a normal part of the sporting experience, and this perception can be a barrier to seeking help (Fawcett et al., 2020).

To highlight this, a recent study on Irish and Australian rowing athletes showed that athletes might not disclose an injury out of fear of being judged as weak. Wilson et al. (2021) studied the experiences of rowers with low back pain (LBP) and found that the athletes described a culture of ‘hardiness’ where they felt as though they needed always to perform, or be ‘bulletproof’. Athletes described being in pain as a weakness, and this was often hidden due to these fears. The title of this study, “You’re the best liar in the world,” provided a summation of this culture, and the lengths athletes would go to to hide their experiences. This environment that the athletes experienced meant they were afraid to be honest.

This nondisclosure phenomenon has also been observed outside of sport in populations of women with endometriosis (Culley et al., 2013). Gilmour et al. (2008) found, in their thematic analysis of interviews with eighteen women, that participants did not always inform employers of their endometriosis symptoms or diagnosis due to fears of being pressured to discontinue work and the difficulty of discussing a gender-specific diagnosis with male employers. Gilmour et al. (2008) also found that this culture of non-disclosure was likely due to negative past experiences of not being believed, being concerned that they would be seen as simply being emotional, being trivialised or receiving little sympathy when they did speak up. The authors found that many participants resorted to finding part-time or flexible work to better accommodate their own needs. While researchers have not explicitly explored whether this kind of concealment occurs

with athletes with endometriosis, considering that a culture of non-disclosure of pain persists in injured athletes and in women with endometriosis, athletes with endometriosis may also choose to keep their suffering to themselves.

Even though the psychological effects of injury have been well documented, supporting athletes through pain with injuries has largely focused on physical rather than psychological rehabilitation. This focus has been shown to prolong recovery rehabilitation (Campbell et al., 2021). Due to the effects of injury on mental health, Hainline et al. (2017) recommend holistic treatment that considers not only physiological but psychosocial influences. However, the reality in sport is that frameworks focusing on physical aspects continue to dominate (Wilson et al., 2021). As endometriosis also has many psychological implications, which are explored below, endometriosis may also suffer from the physical-only based frameworks that overshadow the sporting world.

### **Psychosocial Burdens**

While there is limited research on athlete experiences of endometriosis in sport, there is a growing body of research that investigates women's experiences of endometriosis in general. In line with injuries in sport, the burden of endometriosis is not limited to the physical dysfunctions and symptoms of the disease. Still, it encompasses almost all spheres of life, including quality of life, employment, relationships both with partners and friends but also with healthcare practitioners (Cole et al., 2021; Fernley, 2021; Gao et al., 2006; Moradi et al., 2014) leading to impairments in global functioning (Carbone et al., 2021).

### **Health-Related Quality of Life**

The burden of endometriosis has also been assessed with psychometric measures. Gao et al. (2006) and Charman, Bahram, Moosazade and Bahrami (2017) conducted literature reviews

of the Health-Related Quality of Life (HRQL) burden of endometriosis. Both reviews found that endometriosis had a strong impact on health-related quality of life when investigating areas such as daily activities depression, feelings of uncertainty, and anxiety. Endometriosis poses a significant burden on women and negatively affects all areas of women's HRQL. These findings illustrated how women were impacted by endometriosis not just physically but psychologically, socially, and relationally.

While these results were in line with the previous literature mentioned examining the burden of endometriosis on women, the authors acknowledged that the psychometrics used provided only a snapshot. The actual lived experience, the severity, the surrounding thoughts, or whether the last month was typical for them were not explored here. For example, the psychometrics use wording such as 'depressed', which may not account for those who experience other feelings such as being 'worried' or 'apprehensive'. Using the word 'depressed' may also suggest a severity of symptoms, as opposed to other wording such as 'sad', which may be framed as normative.

Additionally, this research uses frequency over the last four weeks as a quantitative measure for pain and compares scores between individuals. However, a qualitative study by Krebs and Schoenbauer (2020) illustrated the challenges in measuring pain by explaining that pain is influenced by many factors and is challenging to define. These issues create barriers to using quantitative measures to explore pain, as it is an embodied human experience. Both quantitative studies measured one point in time for women's lives but did not acknowledge this as a limitation. The experiences of women with endometriosis can change immensely day to day, week to week and month to month, and over the years, it can vary considerably too (Chopra, 2020). Additionally, the psychometric questions are negatively geared, using language like

‘annoyed’, difficult’ and ‘frustrated’. Some researchers believe that studies should also focus on adaptive functioning and post-traumatic growth and that this disease may have positive consequences to acknowledge (Andysz et al., 2018). While it can be helpful to use instruments to compare between groups, these screens can miss critical information and storytelling. This highlights the need for richer insights into lived experience to be explored.

## **Social Support**

Social and societal supports for women with endometriosis include internet forums, therapists, healthcare practitioners and relationships (Missmer et al., 2021). In addition to relationships with partners, families and friends can be impacted bidirectionally by endometriosis, such that those with endometriosis benefit from support. Still, these relationships can be negatively affected by endometriosis.

Having a partner can improve quality of life, and women with endometriosis often report that their partner is a source of support (De Graaff et al., 2013; Denny, 2004). However, this appears only to be relevant to those who are in self-evaluated healthy relationships. Facchin et al. (2021) observed that those who evaluated their relationship as negative experienced poorer psychological health. Additionally, endometriosis appears to be a contributor to negative relationships as studies report that related symptoms put pressure on relationships and, in many cases, contribute to relationship breakdowns (Cox et al., 2003; Denny, 2004; Huntington & Gilmour, 2004).

Research that has been completed on the effects on male partners has been scarce and somewhat controversial for centring on men (Cockburn, 2017; Culley et al., 2017; Keany, 2019). Culley et al. (2017) found that men had to take on additional support roles and experienced emotions such as anger, worry, helplessness and frustration. This may, in turn, add more stress to

the relationship and the person already suffering from endometriosis. In contrast, Hudson et al. (2016) found that those with a supportive partner who could maintain financial security could step back from their employment commitments or make suitable changes.

Research into chronic diseases, in general, has shown that those suffering generally adapt better to good social support (Gil et al., 1987). Additionally, while social support through relationships usually acts as a protective factor in health, research has found that many women with endometriosis have felt unable to be honest with friends and family about their symptoms due to feeling misunderstood (Grogan et al., 2018; Reblin & Uchino, 2008). As social support can moderate or exacerbate pain, this withdrawal can lead to a self-perpetuating cycle where pain increases and can lead to more social isolation (Wallace et al., 2014). Missmer et al. (2021), who reviewed eleven studies about the impacts of endometriosis on social life over the life course, confirmed this. The authors noted that women experienced social impairments due to several factors, including physically struggling to attend events, incapacitating pain, fatigue, bleeding, depression, low self-esteem, poor body image and lack of self-confidence. In terms of athletes, injury research has shown that athletes often socially isolate when injured, leading to feelings of lost identity and lower levels of support (Gould et al., 1997; Mankad et al., 2009).

## **Employment**

In terms of the impacts of endometriosis on work, research has shown that endometriosis is a cause of significant disturbances in employment for sufferers (Andysz et al., 2018). Hansen et al. (2013) found that, compared to population groups, women with endometriosis took significantly more sick leave due to their pain. Nearly 60% of participants noted that pain impaired their work efficiency. For half of the respondents, pain also influenced their ability to

concentrate, and responses suggested that frequent pain, fatigue, and depression at work were linked to decreases in their ability to work.

Furthermore, Fourquet et al. (2010) found that pain was the main reason for absenteeism for 60% of their 107 survey respondents and later found that the average lost time was considered to be 7.41 hours during the week where participant's symptoms were at their worst. Other studies have demonstrated that 51% (De Graaff et al., 2013) and 66% (Fourquet et al., 2011) of participants experienced pain-related difficulties at work. In terms of severity, between a third to nearly half of women rated the impact of their endometriosis on their work as severe (Caserta et al., 2013; Fourquet et al., 2011); indeed, Caserta et al. (2013) reported that only 12% of the 222 participants reported no impact of endometriosis on their work.

In addition to pain affecting the ability to attend and complete work, women have also reported adverse mental effects related to their suffering of endometriosis in their workplace. In the Hansen et al. (2013) study, women reported a sense of guilt and embarrassment about their ability to function at work. Of the 610 diagnosed endometriosis participants who responded to their online questionnaire, 31% felt worried because of their inability to work due to the pain, and 30% felt guilty about taking a day off because of the pain. Even more worryingly, Facchin et al. (2019) found that women with endometriosis were less likely to be employed than women without endometriosis. This was also observed by Rowlands et al. (2022), who found that a surgically confirmed diagnosis of endometriosis was associated with unemployment following the diagnosis in a 20-year longitudinal study and attributed this partly to poor support for women with endometriosis in the workplace. The authors acknowledged a reduction in quality of life for those who stay at work due to pressures. These effects have been shown to worsen progressively for those who remain employed due to financial pressures (Kubicek et al., 2010). As

endometriosis is a progressive disease, the likelihood of being unable to work could potentially increase over time (Koninckx et al., 1991). If this is the case in sport as well, it could be that athletes can no longer continue in sport as the disease progresses. Moradi et al. (2014) provided an example that two women gave up the opportunity to continue in elite sport. However, they did not elaborate on their reasons for leaving sport and whether it was related to endometriosis. Accordingly, the effects on sport are currently unaccounted for in the literature.

Additionally, women in the workplace have found that their employers dismiss or even diminish their symptoms, causing them to change or quit their jobs (Gao et al., 2006). While coaches are often viewed as part of the support network of athletes, in the context of elite sport, coaches usually take a leadership role, similar to that of a boss in a work environment. Therefore, endometriosis may affect athletes' relationships with their coaches and staff, similarly to how people with endometriosis are influenced by their employer or boss. Granito (2002) found that athlete-coach relationships changed following injuries, especially for females. Of the sixteen female participants in the study, 94% reported that they were less satisfied with the coaching relationship after getting injured. These women reported that they felt their coaches no longer had time for them and ignored their needs making them feel invisible. In addition, Udry et al. (1997) found that athletes saw their coaches as distant, demonstrated a lack of belief in them, were insensitive to their injury and provided substandard rehabilitation guidance. As endometriosis is a progressive disease, it would be interesting to investigate whether coaching relationships deteriorate alongside symptoms, given the progressive nature of endometriosis.

## **Sleep**

Sleep is a vital physiological process for all humans but especially for athletes, as quality sleep is critical for recovery from training and, therefore, performance (Montagna &



Chokroverty, 2012; Watson, 2017). Sleep impacts emotional regulation, cognitive performance, physical development, and quality of life. It drives adaptive processes between training sessions, reducing the risk of injury and illness in athletes (Watson, 2017).

Disrupted sleep is a common issue for women with CPP, and recent evidence shows that this is also a common complaint of women with endometriosis (Cosar et al., 2014; Nunes et al., 2015). Nunes et al. (2015) evaluated sleep quality and found that in their evaluation of 510 participants, 257 of whom had a diagnosis of endometriosis, that sleep was significantly poorer in the endometriosis group. However, sleep quality is only one component of sleep and other aspects such as insomnia and daytime sleepiness were not investigated in this study. This research was expanded on by Maggiore et al. (2017), who found that these aspects of daytime sleepiness and insomnia were also negatively impacted in participants with endometriosis. They also found that those with endometriosis were more likely to need sleep medications. Impacts on sleep were correlated with the intensity of their pain, and the authors proposed that the pain and effects on sleep become a vicious circle where pain increases sleep problems, and limited sleep increases pain. This study acknowledged that they did not control for factors that may confound the results, such as mood disturbances, which have been independently associated with more depressive symptoms (Arion et al., 2020). The authors acknowledged that future research could be supported by investigating such influences. Their study was strengthened by using reliable self-report measures and including participants only with a diagnosis of endometriosis.

Interestingly, Maggiore et al. (2017) identified that a strong influencer of sleep quality was exercise. The authors proposed that it was helpful in improving sleep because exercise influences melatonin, the sleep hormone, production. In terms of how this may affect athletes, where evidently, exercise is part of their daily life, it is unclear if there are limits to these effects.

It may be that exercise in moderation is helpful, but as excessive exercise breaks the balances of energy utilisation, exercise in extreme amounts may have the opposite effect (Wang, 2017).

## **Conclusion**

This literature review explored the limited research on athletes with endometriosis. Due to the lack of literature available specifically, a broader scope considering both the experiences of endometriosis on women's lives and the impacts of pain on athletes was considered. Additionally, little research outside the scope of medical science exists to explore endometriosis and the lived experiences of those suffering from it. Overall, this review illustrated the burden that it is to live with endometriosis. About one in ten women is diagnosed with endometriosis, yet many more are likely to unknowingly suffer from this disease (Viganò et al., 2004). These women often endure years of debilitating pain and other symptoms like fatigue and infertility (Bulletti et al., 2010; Jones et al., 2004). On top of this, women are forced to battle for a diagnosis, often experiencing delays for many years, only to be misdiagnosed, or to find that having surgery was unsuccessful in completely alleviating their pain (Agarwal et al., 2019; Bulletti et al., 2010; Chopra, 2020).

Despite advances in modern medicine, women are hampered by outdated perspectives and treatments that are based on ancient theories of women being hysterical (Alimdjanovna, 2021; Beecham, 1949; Nezhat et al., 2011; Vercellini, 2015). These challenges compound to, unsurprisingly, create a burden on the quality of life of women with endometriosis (Moradi et al., 2014). This burden affects almost every area of life from developing and maintaining relationships effecting everyday functions such as employment or sleep (Facchin et al., 2018; Grogan et al., 2018; Koninckx et al., 1991; Maggiore et al., 2017; Nunes et al., 2015).

While research on how endometriosis affects the lives of women is growing, we still

know less about the effects on athletes specifically. The single study identified on this topic did little to provide an explanation of how endometriosis affects the experiences of athletes (Jones et al., 2007). Due to this, athlete experiences of pain in general were explored. Athletes suffer from their injuries, not just physically with reduced performance, but with practical implications like being deselected, and additionally experiencing psychological impacts (Fruchart et al., 2020; Hainline et al., 2017; Igolnikov et al., 2018; Von Rosen et al., 2018). Some of the psychological impacts include burnout (Cresswell & Eklund, 2006), mood disturbances such as tension, anger, depression and low self-esteem (Smith, 1996) and even post-traumatic stress disorder or other trauma-related mental disorders (Aron et al., 2019). To add to this, athletes also have to navigate a world where their pain is often trivialised, minimised or even dismissed (Gervis et al., 2020).

This lack of currently available research on athletes with endometriosis is what motivated me to pursue the current study. Many studying endometriosis consider it to be an enigma or a mystery (Chopra, 2020; Jones, 2015), and so I hope to provide a critical feminist view that centres on the voices of women and their lived experiences. As in my own experience, and those of peers, navigating endometriosis without clear guidance or direction from the research created a challenging experience. My hope is to provide the first step in researching this area with the aim that future research is spurred on by this study.

### **Chapter Three: Methods**

This chapter begins with an explanation of how this study was conducted and the rationale around procedures. Following this, ethical considerations are explored. Next, I discuss how critical realism framed my knowledge of athletes and endometriosis and discuss how feminist theory impacted my understanding of research with women and my goal of amplifying women's voices. Following this, I explain inductive reflexive thematic analysis (Braun & Clarke, 2006; 2019) and why it was a helpful tool to analyse my data. Lastly, I explore reflexivity and give a summary of the ethical procedures that were undertaken to complete this research.

#### **Procedure**

I used social media advertising to recruit participants, using advertisements (Appendix A) that included details of my research and inclusion criteria. From here, the advertisements were posted on my personal social media accounts and others shared these around the web on Instagram, Twitter, and Facebook. Participants responded to me via email or social media. Following this, I communicated by email and sent a link to the online consent and transcript release form on Qualtrics (Appendix B) and the information sheet (Appendix C).

The inclusion criteria were: being a female athlete at the national or international level with an endometriosis diagnosis and being over the age of 18. In an attempt to increase the diversity of participants, I did not stipulate any other factors such as: length of time with endometriosis, stage, sport, country of residence, ethnicity, or any other factors. I aimed to recruit seven to ten participants. As the scope for this project was relatively narrow and the aim was to gather rich data through the sharing of in-depth experiences (Malterud et al., 2016), my supervisor and I agreed this was a manageable size for a thesis project. I initially recruited 11

participants, but two dropped out before completing the interviews. There was no specific explanation for dropping out, but responses ceased so withdrawal was assumed.

Participants were aged from 21 to 36 with an average age of 27. Participants resided in New Zealand, Australia and the United Kingdom and competed in Elite sports ranging from National Championship to Olympic level. Sports included athletics, gymnastics, rowing, martial arts and cycling (including track, road, and mountain bike). After participants viewed the information sheet and signed the consent form (distributed as a Qualtrics form), I made appointments with each of them to complete the interviews via Zoom. The interviews were recorded on Zoom and were scheduled to take 60-90 minutes. I chose Zoom for accessibility as participants were geographically distributed and local restrictions due to the Covid-19 Pandemic which meant in-person interviews were not an option. While many consider online interactions to be less personal, some qualitative research has described online interviews as highly satisfactory for building rapport and developing connection (Archibald et al., 2019). In my study, participants appeared to engage openly and honestly and shared their highly personal experiences in great depth. I planned plenty of time to interview participants and used a semi-structured interview plan (Appendix D) as a guide. As the interviewer, I aimed to speak as little as possible, allowing participants' accounts to guide the process. I aimed to use as much non-verbal feedback e.g., nodding, as possible in order to not disrupt the Zoom audio, and to encourage participants to expand on their experiences.

The interviews began with asking participants how they were, and if they wanted to make a hot drink before commencing. Next, we shared whakawhanaungatanga where I shared about my own journey to initiating this research and mentioning that I also was an athlete with endometriosis. Participants were welcomed to introduce themselves. The aim of this was to build

rapport and create a calm setting where participants felt relaxed. This was followed by asking some general questions regarding their age and sport and why they were drawn to participate in my research. These questions were designed to get to know participants and personalise my future questions in a way that was relevant to their sport.

The next section of the interviews was about their experiences with endometriosis, using broad questions designed to elicit detailed responses (Polit & Beck, 2009). The interview guide is provided in appendix (D). Some participants spoke openly and shared in detail. For those who needed some encouragement to expand on their experience, I asked questions such as “what was that like for you?”, or “can you expand on that?” which usually prompted participants to share more. For the first three interviews, I asked about symptoms, journey to diagnosis and treatments, but as the interviews went on, I amended the way I asked questions to be broader, for instance “tell me about your journey to endometriosis”. I found that by asking in this way, participants would tell me their story in their own format, including many of the answers to my questions, and if they left something out, I would ask it before moving on to the next section. I found that, when asked in this format, participants told their story in greater depth.

The subsequent section in my interview guide was about how endometriosis had affected the participant’s life as an athlete. In this section we covered relationships, pay, selection, willingness to continue in sport, how their symptoms affected them and whether having endometriosis affected any other aspects of sport. The last question was regarding how endometriosis had affected their wellbeing or mental health. I used prompt words like happiness, connection, sense of purpose, physical and mental health, emotions, and sense of security. After the first two interviews, I used additional prompt words including mental health and stress.

In the final section of the interview, I asked participants how they may be affected by

endometriosis in the future and if they had any advice for their younger selves or other women suffering from endometriosis. These questions were a good way to focus on something more positive after sharing what was often a sensitive story. I ended each interview by asking if participants had anything more to add. Following this, I suggested that I turn the recorder off and give the participants a chance to ask any questions. If something interesting came up, I asked their permission to begin recording again, then ended with the same question, “Is there anything else you’d like to add?”.

To conclude the interview, I thanked participants for their time, for contributing to my research, for sharing their very personal stories with me and entrusting me to do good mahi (work) with their information. Most times participants also thanked me, and some said they had not shared their story before and that they felt encouraged after doing so. I sent participants a gift card (grocery voucher or similar) as a small honorarium valued at \$40NZD to thank them for their time and for sharing their stories.

After the interviews, I transcribed the audio recordings from Zoom word for word. I used orthographic (verbatim) transcribing technique to write word for word what participants had said. Spoken language is far messier than written and I wanted to record in a way that portrayed what participants actually said rather than how I may have written it. Every ‘um ’and ‘ah ’was transcribed (Braun & Clarke, 2013). Two participants stated on their Qualtrics form that they wanted to view and be able to edit a copy of their transcriptions. I sent these back to participants for review and gave them two weeks to get back to me if they had any changes they wanted to make. I said in my email that if I did not hear back from them within the two weeks, it would be assumed that they were happy with their transcriptions. I did not hear back from either participant.

During the analysis, I used the principles set by Noble and Smith (2015) to ensure good reliability and validity of my research. These included accounting for personal biases that may have influenced the ways in which I conducted my research and interpreted the findings. These biases can be considered as strengths and/or weaknesses and are addressed in the reflexivity section below. It also included record keeping. I did this by creating an excel spreadsheet to document each step of the research process and to make sure I had followed through on my responsibilities to participants, for example providing the honorarium and returning transcripts when requested. In addition to returning transcripts, Noble and Smith (2015) recommend that participants be invited to make edits to the transcripts. I provided this opportunity to all participants, however, no amendments were requested.

Additionally, Noble and Smith (2015) advise the use of verbatim quotes to support findings. Verbatim quotes are a basic source of raw data in qualitative research that serves to illustrate the experiences and emotions of participants (Patton, 2002). I viewed this as particularly important with critical realism guiding my research as I will describe below. Using these verbatim quotes, I decided to embolden key statements within the quotes for emphasis and ease of reading.

## **Ethics**

Ethical approval for this project was assessed according to Massey University guidelines via High-Risk Notification. Extended interviews about sensitive topics can be perceived as intrusive or stressful (Legard et al., 2003) and a full ethical application was deemed appropriate for this study. Participants were over the age of 18 and were able to give informed consent and did so on the Qualtrics form (Appendix B). On this same form, participants were able to request to edit their recordings.



My main ethical concern was the possibility that participants could experience harm. From my own experience and reading the literature I know that experiencing endometriosis can be the cause of significant distress. Due to this, I added New Zealand distress lines and an international directory of distress lines to my information sheet. However, I knew that some participants may not have read the information sheet fully or may have forgotten what it said by the time of the interview. I also considered that some participants may have thought they would be fine beforehand and then realised while talking that their experience was distressing. Due to this, I sought to create a calm environment at the start of the interviews and aimed to finish on positive aspects. I also allowed extra time for people to ask questions and I made sure to ask how participants felt at the end of the interview. In my information sheet I mentioned that I have endometriosis and am an athlete myself. I hoped by sharing this information that participants would feel comfortable speaking to someone who could relate to their experiences.

An additional ethical concern was experiencing harm myself. I considered that the interviews could be distressing to hear about the negative experiences of others, so I made time to see a psychologist in case anything came up. An appointment was not needed in the end, but knowing the option was there was comforting.

Cultural competency was also an ethical concern of mine. I completed cultural consultation with Pita King, a Māori lecturer at Massey University. During this consultation session we explored considerations for conducting the research in a culturally sensitive way. Additionally, I used Te Ara Tika guidelines to help formulate questions during the consultation (Hudson et al., 2010). Pita provided a constructive critique of my proposal and explained how it may affect Māori. Because my study included people from a variety of cultures, I applied principles that we decided would be appropriate for Māori across all participants. This included

whakawhanaungatanga, creating time for getting a drink at the start of the interview and creating space for questions at the end. In addition, I made sure that key information was presented in the information sheet and asked them if they had any cultural requirements, to which all participants said no. I then explained to participants what would happen with their information after the interviews were completed.

In terms of preserving participant confidentiality in my writing, a previous experience shaped my own work. In another study, I found that even though the researcher used pseudonyms, some identifying details in quotes were left in, which meant that those in the study may have been able to identify other participants. As the study was on a sensitive topic, for some participants, having their identities known could cause harm. The world of sport can be small and giving out details that may not seem important to a researcher, like the name of a championship, can quickly reveal to others in that sport the identity of the participant. This experience made me particularly attuned to how I was managing confidentiality in my own research. I used pseudonyms for each participant. I additionally went to extra effort to privatise the identity of participants by removing keywords from their quotes, including the name of their competition, their location or other personal information. I believe this helped to keep participant identities anonymous. To work toward an effective approach to preserving confidentiality in research on sport, I followed the lead of a study that achieved a good balance of detail and removal of identifying information. This study was conducted by Moradi et al. (2014), who removed details like sport name, team name, championship name and even the year of surgery for the participants.

I stored participant information my password protected computer. Following the Zoom interviews, I saved the recordings to my computer and deleted them from my Zoom account.

Following this, transcripts and participant information was stored on a password protected computer and will be deleted in up to five years.

For me personally, this research was not only about gathering data, but building relationship and solidarity in the endometriosis community. So when, during my analysis, I found that two participants shared similar experiences with the rare type of endometriosis they had, and had related feelings such as ‘no one understands,’ I felt as though those two participants could mutually benefit from confiding in each other. I asked for approval from the research ethics office that approved this research to share their contact details with each other with the consent of the two participants. Both consented and thanked me for linking them together.

## **Methodology**

My research was anchored by the philosophical assumptions of critical realism (CR). While CR was not used inflexibly, I drew on the related principles of CR from the work of Bhaskar (1998). The principles of CR suggest an ontology where the world is seen in three realms defined as the ‘empirical’, the ‘actual’ and the ‘real’ (Bhaskar, 1978). The ‘empirical’ is what is experienced by individuals on the surface level which we can observe, this reality is filtered through the lens of human interpretation and experiences (Bhaskar, 1978; Peter & Park, 2018). The ‘actual’ is considered to be events that may or may not be experienced which presents a reality where no filter exists and events occur whether experiences are attributed to them or not (Fletcher, 2017). Finally, the ‘real’ is considered to be causal powers that create events and experiences at the empirical level (Bhaskar, 1978; Hood, 2012). This means that the perceived realities at the empirical level and the causal mechanisms that underlie these can both be engaged in as CR provides recognition that objective and subjective realities co-exist (Peter & Park, 2018). The theory of CR suggests that within the social world and natural world, there are

unobservable events which have causal properties, which cause events that we can observe (Bhaskar, 1978; Leung & Chung, 2019). Therefore, the stance of CR is that our perceptions of reality can change due to unobservable influences including our values, commitments, mental state and individual ideology (Maxwell & Mittapalli, 2010). CR seeks to investigate these underlying influences and mechanisms that may or may not impact social outcomes (Elder-Vass, 2010). In the context of this study, the empirical included the events that participants experienced, like being diagnosed with endometriosis or having surgery, and their experiences and observations of these events. The ‘actual’ were events that were generated by the ‘real’, the hidden mechanisms and structures that influenced them including masculinised knowledge and structures of sport.

Some, including myself, view CR as both ontology & epistemology (Braun et al., 2019). Ontologically, I come from the view that truths are contextualised and individual. Epistemologically, I am working to find multiple answers and views while highlighting the unique experiences of women athletes with endometriosis. In terms of applying CR to research, CR has been used to consider the influence of social structures and powers that govern or influence others (Leung & Chung, 2019). CR fits well with the aims of this study, as endometriosis is a complex condition with influences of not only the self, but others including support networks, social expectations, and those in positions of power such as coaches or HCP. In particular, the masculinised knowledge of medicine and notions of hysteria form a social structure that those with endometriosis must navigate (Chopra, 2020; Davis-Floyd & Sargent, 1997; Young et al., 2019). Women with endometriosis have to compete with this structure to feel heard and to receive adequate care (Cole et al., 2021). Accordingly, women with endometriosis find they have to adhere to social norms, which appear to condition their thoughts and

behaviours (Elder-Vass, 2010; Young et al., 2019). As social norms tend to be consistent for at least a period, we can use these to make assumptions regarding how those norms may impact people (Elder-Vass, 2010). Therefore, the research questions in this study can be addressed and the underlying mechanisms can be considered.

CR, combined with feminist theory, considers the world to be of depth in that experiences are complex and the 'real' cannot be reduced only to experiences that have no external influence (Parr, 2015). Feminist theory, by highlighting the accounts of women, theorises about the structures that oppress women and maintain the power and influence of masculinised systems (Parr, 2015). These structures are 'real' in that they are not material but have power and influence individuals, albeit not necessarily in a straightforward manner (Sayer, 2010).

Feminist theory aims to reduce sexist research biases and magnify women's voices (Campbell & Wasco, 2000). In practical terms, feminist research has been identified by Campbell and Wasco (2000) as having some essential characteristics such as: facilitating trust and disclosure by reducing hierarchical relationships between participants and researchers and reflecting upon and recognising the uniqueness of women's lives. A facet of feminist research is the 'embodied health movement' which helps to facilitate collective identity around shared experiences (Whelan, 2007). The embodied health movement addresses disease or illness experiences by challenging existing medical knowledge and science and placing emphasis on those who experience the disease (Brown et al., 2004). This collective identity can help to challenge norms and promote the development of embodied knowledge (Whelan, 2007). A feminist theoretical lens in this analysis seemed appropriate as it aims to understand some of these shared experiences and embodied experiences in the hope of creating a sense of solidarity among athletes with endometriosis.

## Analysis

The CR approach that I took has similarities to social constructionism in the way that language is understood to create or construct reality, but CR argues that these constructed realities are constrained by the real world which has limits (Sims-Schouten et al., 2007). The realities of the physicality of sport and the experiences of endometriosis may constrain the construction of reality and make some methods of storytelling more likely than others. As a researcher with endometriosis and an athlete myself, the lens through which I view a story may not only be different to another, but I also cannot access the objective reality of my participants. I am only able to understand a glimpse of their social reality which is also constrained by social contexts (Willig & Rogers, 2017).

While analysing and coding the data, I tried to present the data for what it was. However, I do acknowledge that as a sufferer of endometriosis myself, and as an athlete, I could relate a lot to participants' experiences and was emotionally engaged in their story. With this in mind, I acknowledge that the interpretation of the data is entirely my own and is influenced by the experiences that I have had in my own life, combined with learning from research. While many qualitative researchers posit that analysis ends when a saturation point is met (Saunders et al., 2018), I did not believe that this would ever occur. The data was rich and meaningful, and I interpreted what I could, however I also acknowledge that if another observer was to look at the same data, it is likely that their analysis would differ to mine based on their own conceptions, understandings, and experiences.

I undertook a reflexive thematic analysis of the data ((Braun & Clarke, 2013). This approach to TA includes six stages: familiarisation, code generation, theme development, reviewing and defining the themes, and finally writing of the analysis. These steps helped to find

meaningful patterns, ideas, themes or concepts within the data (Braun et al., 2014). One of the benefits of this method is that it can be used in an inductive way where codes and the themes can be constructed from the actual data of the participants, as opposed to having a pre-determined coding system. Firstly, I made myself familiar with the data by listening to the audio transcripts, transcribing verbatim, then listening again to the transcripts and writing down ideas that came to mind. Getting to listen to the recordings again helped me to reflect and think about each participant's journey individually and collectively. When listening and reading through transcripts, I related a lot to the experiences of the participants and noted these reflections in my private journal.

Following familiarisation, I used NVIVO to generate codes during a systematic analysis of the data, reading it line by line. Following this I grouped these codes into larger themes and then into broader categories. I then printed and cut out individual quotes that I believed to be relevant and sorted them into five general categories or groups of ideas. From these categories, I developed five themes and then reviewed these again. Upon a second and third review, I arranged the data into four themes as, upon deeper reflection, the fifth theme did not offer anything unique to the other four themes. After grouping the printed quotes into four themes, I then arranged them into subthemes. I observed many similarities between the stories of participants within the themes and used these to arrange the subthemes according to the experiences that were highlighted to me. I decided to combine results and discussion in part due to the lack of comparable research on athletes with endometriosis. Finally, upon a significant period of reflection, I completed the concluding chapter with implications, strengths and limitations and final remarks.

## **Reflexivity**

Reflexivity requires researchers to acknowledge their role in research and understand that their beliefs, assumptions and experiences contribute to their work (Watt, 2007). Reflexivity is an important feature of critical realism (CR). CR carries some of the features of social constructionism where language constructs reality, the main difference is that CR argues that these realities are limited by the “possibilities and limitations in the material world” (Sims-Schouten et al., 2007p. 102). CR recognises that social structures may influence discourses and that in research, we can only view the constrained social realities of participants rather than an objective reality (Cole et al., 2021). CR encourages explanations of social relations that relate to real world issues (Wiltshire, 2018).

Reflexivity is, not only, a critical examination of the whole research process but a critical self-reflection on theoretical predispositions, preferences and biases (Schwandt, 1997).

Reflexivity is additionally the acknowledgement of the researchers place in the context and social phenomenon that they seek to recognise (Schwandt, 1997). This critical reflection seeks to illuminate rich meaning about theoretical, ethical, personal, and epistemological aspects and represent a methodical process of learning about myself as a researcher (Kleinsasser, 2000).

In my own case, I am an athlete who has endometriosis. While considering reflexivity, this specifically came to matter. I grew up in New Zealand where I have lived all my life, other than spending periods overseas to participate in professional sport. I am a pākehā, cisgender, straight, non-disabled, middle-class female and have my own experiences with endometriosis, which inform my perspective on the disease. My experiences with endometriosis and the effect that it had on my sport created exceptional challenges for me, which inspired me to complete this project and gave me the ability to empathise with participants.



Having said this, this experience also comes with biases that I would like to acknowledge. My 'insider' experiences likely shaped how I designed and conducted the interviews. Feeling a sense of connection to some of the participant experiences likely meant that I highlighted those experiences in my findings. Additionally, I observed many differences in participants' experiences compared to my own. These stood out to me, and I spent significant time considering how my journey may have been if I had had those experiences. This was to the extent that I likely focused on differences during my reflections more than similarities. In my analysis, however, it was the shared experiences of participants that I wanted to emphasise. As previously mentioned, it was an additional goal of mine to create a sense of solidarity among the small community of athletes with endometriosis.

Another issue that resonated strongly with me was simply how hard the experiences were for participants. This was first made clear to me during the literature review. Reading the research at times was mentally exhausting, and I found myself having to take breaks. Completing the literature review took significantly longer than expected. I realised, in hindsight, that this was due to a kind of avoidance. I knew the literature would be hard to read, but at times I found it depressing as if, despite the efforts made, there was possibly no hope for the future of this field. I did, however find the motivation to continue onwards, with the slight hope and constant reassurance that presenting these stories may help, even just one person. I knew that personally, if this research was available to me, at the height of the burden that I had experienced with endometriosis, it would have provided me with some insight, knowledge, or advice at best, and at least a sense of solidarity and that I was not alone.

This feeling of mental exhaustion happened two more times during the process of this study, when I interviewed participants and again during the analysis. I often found myself, on the

one hand, relating to the experiences of participants and, on the other hand, feeling absolutely outraged that this happened to them. The participants I spoke with were strong, physically, and mentally, and to hear how they had been continually minimised and invalidated was infuriating. This fuelled the fire, as such, of motivation for me to complete this research, in the hope that ‘getting the ball rolling’ may, firstly, inspire others to listen to those suffering from endometriosis, and secondly, to take them seriously and create actionable steps to reduce the needless suffering.

## **Chapter Four: Findings**

This chapter will detail the main findings of this research on athletes' experiences with endometriosis. Participants shared their experiences in detail and depth through a series of interviews that took place online on Zoom. During the interviewing phase of my research, I observed that all participants went through similar experiences. For instance, participants began by describing ways in which they normalised or minimised their experiences of pain and burden. At some point in time, however, a person or an event influenced them to realise that what they were experiencing was not normal. This led to a phase of contemplation and information seeking. Lastly, participants described feelings of relief and frustration at their diagnoses and shared their thoughts and advice about the future.

Noticing the shared experiences in participants' stories informed my arrangement of four themes. Accordingly, the themes illustrate participants' experiences throughout their journeys. Notably, this was not necessarily a linear process; participants occasionally went back and forth through these experiences. Through conducting a reflexive thematic analysis, I developed four themes that relate to my research questions (Braun & Clarke, 2013):

Theme One: "A Cloud Over You" The Burden of Endometriosis

Theme Two: "How was your Holiday?" Experiences of Invalidation and Minimisation

Theme Three: Recognising "Maybe This Isn't Normal" Advocacy and Overcoming

Theme Four: "Thank God I've Got an Answer" Misdiagnoses, Diagnoses and Treatments

Theme One describes the physical pain participants experienced and how that pain affected their mental health. Following this, Theme Two describes how participants were often invalidated and minimised by those around them, particularly from HCP, coaches, support staff, friends, and family. Theme Three explains how participants reached a turning point in their journey by

realising that their experiences were not normal. This theme details why this took so long, and the self-advocacy required to achieve change. Theme Four firstly explains the difficulties participants experienced while searching for help before describing participants' experiences of receiving a diagnosis of endometriosis. Lastly, Theme Four illustrates the feelings of relief experienced when they finally received this diagnosis.

### **Theme One: “A Cloud Over You” The Burden of Endometriosis**

Participants described endometriosis-related burdens in a way that I liken to a rain cloud that precipitated on every part of their story. Part of this burden was the time-consuming or debilitating effects of having a disease, but the overarching burden was pain. Pain influenced and tainted each experience with hardship. Participants described their physical and psychological pain in many ways. Some experienced different types of pain on different days, and some were hit with many pains at once. Some of the descriptions included: “a neural kind of pain, like a sharp electric shock”, “like my internal organs were bleeding”, and “like someone is like grabbing all my organs and sort of like, wringing them like a tea towel”.

Participants in this study described their pain in detail. For some, it was more of a nuisance or worry, but for others, it was debilitating to the point that it affected daily functions like training, sleep, and relationships with others. The participants often noted their attempts to minimise or normalise this pain and how the load of these burdens was often not shared with many others. Participants kept their pain primarily to themselves or just a few trusted others. As athletes, these women described going to great lengths to hide their pain due to fear of being considered weak. Weakness and emotionality have been described as stereotypically negative female traits (Cole et al., 2021).

Theme One is underscored by two subthemes: first, pain and the related burden of endometriosis and how this impacted the ability to function; second, how endometriosis impacted participants' mental health.

***Subtheme One: “Somebody Twisted a Knife in Me” The Pain of Endometriosis***

Participants experienced severe and debilitating pain along with other symptoms like constipation, mood changes, painful sex, fatigue, and heavy bleeding. While these symptoms are well noted in the research (Bulletti et al., 2010), participants did not describe other commonly-reported symptoms like dysuria and infertility. It is possible that most participants in this study would not yet be sure if they had fertility issues, as most were still active in their sport. Participants also reported experiencing a “bloat stomach” (Briar) and “looking pregnant” (Chloe). Having a “bloat stomach” has been identified by others with endometriosis and is known colloquially as ‘endo-belly’, where swelling and inflammation can cause the abdomen to expand (Ek et al., 2015). Additionally, there was one participant who experienced a rare symptom of bleeding nipples (Alex).

The most common symptom of endometriosis that participants reported was chronic pelvic pain (CPP). This aligns with prior literature on endometriosis (Jones et al., 2007). CPP and other pain caused significant distress to all participants. Participants described their pain in many different—and particular—ways ranging from burning to stabbing. Aroha explained how she experienced three different types of pain: “a neural kind of pain like a sharp electric shock,” also “an ache and pain that kind of like would wind up and up and up,” and additionally “like someone is like grabbing all my organs and sort of like wringing them like a tea towel”. Liz said it was “the worst pain in my life because it feels like I might die”. Tiana described how her pain came in episodes and described one as:

You know the feeling when you need to go to the toilet right and it's kind of like a painful but kinda **like a burning sensation** inside and I was like man like do I have diarrhoea what is it and so I went I feel like **I'm about to vomit and I couldn't breathe** and so I was like oh this hurts like a lot and so I was like **I'm gonna die** I grabbed onto the wall and said I can't breathe like it's so painful.

In describing her pain, Tiana relates her experience to one that people without endometriosis might be familiar with; at the same time, her description emphasises the extreme nature of the pain. She refers to how the level of pain made her feel like she was going to die. Such a level of pain is far above what one might be expected to handle, illustrating the intensity of this experience for participants like Tiana. Additionally, Anna experienced pain that came and went and had trouble breathing during the pain. Anna said, regarding one of her painful episodes:

At the time **it was agony** it was **the most pain I've ever been** and it was like somebody **twisted a knife** put a knife in me and just twisted it and I couldn't breathe or move without it spasming.

Like Tianna, Anna evidences the intensity of her pain through the use of emotive language (“literal agony”) and metaphors (“somebody twisted a knife”). Ella likewise described her pain as “extreme” and as worsening throughout different times in her menstrual cycle.

I had a really **extreme burning sensation** kind of a ‘V’ shape around there [pointing to her lower abdomen] and that would get worse at that like that was at an ache constantly and it would get worse over bleeds and ovulation.

Two participants, Anna and Alex, both experienced diaphragmatic endometriosis (DE). Endometriosis on the diaphragm is considered rare and for many, is asymptomatic (McKee et al., 2022). However, both Anna and Alex experienced severe pain, which was disabling and caused

pain with heavy breathing—particularly consequential for athletes, who often exert themselves.

Alex described her experience as:

Getting pain in my diaphragm not just when I was on my period it would have been like when I was training hard and then it would get worse during my period and in April it lasted for like it was like half hour episodes for like three hours every five hours or something and I just was like on the floor unable to move like something and my boyfriend had to call the 24 hour line [emergency services] to take me to hospital because like at that point I still didn't know what it was and like the only way I can describe that pain is like it felt **like I've been really severely beaten up and like my internal organs were bleeding** it's like that is that is the only way I can describe it and it's obviously really scary because I didn't want to...it was like not being able to take a full breath or like not even a full breath like **not being able to breathe** like a normal person and it was pain in my diaphragm like under my right ribs and then each month of my period it just got like more severe and I could breathe less and then I was having to be on like the last month I had my period I was having to just like I was constantly on Ibuprofen and Paracetamol for like five days because I was like if I didn't take them on time then the pain would come.

Participants described how their pain and the related burden lingered over and tainted many areas of their lives; it was described as “a cloud over you” (Anna). Participants described in great detail how sometimes, the pain was more of a nuisance or worry, but other times it was debilitating to the point that it affected daily functions like training, racing, sleep, and their thoughts. As Aroha described: “I was literally just about getting through training and then I just had no energy to do anything else”.

One of the critical areas of function that was impacted was sleep. Participants experienced so much pain at times that it prevented them from being able to sleep. For instance, Briar reflected on how: “at night-time I would just lie there in bed with a hot water bottle where you get to the point where you thought **you're just going to pass out or you wanted to cry**”. Participants described how their sleep was negatively impacted by severe pain; disruptions to sleep are widespread amongst people experiencing chronic pain – over half of those with chronic pain experience disturbance of sleep quality or duration (Cheatle et al., 2016). These disturbances also have consequences beyond simply feeling tired; one participant noticed how her reduced sleep would increase her other symptoms: “I make sure I sleep well because if I don't sleep very well, then I find that I get all the gastro like gastro sides just flare a little bit more so mainly bloating” (Dani). Briar additionally described how the cycle of pain would impact her ability to race at her best, initially by impacting sleep, in turn affecting recovery, and, ultimately, her performances:

And night-time it was affecting things like sleep because you're in so much pain you're just lying there and definitely affected if you're coming into a race and it was coming into that time a month or even in the lead-up or could definitely notice it and I think I'd be off my game if it got really bad.

Sleep is also a critical factor in sporting performance. Reduced duration or quality of sleep, especially over long periods, can severely impact performance by increasing fatigue, increasing the likeliness of illness or injury and limiting the ability to recover from training (Watson, 2017). Given this, participants who experienced sleep impacts likely experienced reduced recovery from their training. Additionally, it is well known that poor sleep has a ripple effect on other areas of function such as emotional regulation, cognitive performance, physical development, and quality



of life (Watson, 2017). These impacts also influence other areas of function described below, such as training, racing, and mental health.

Disruptions to sleep were not the only consequence of the intense level of pain and symptoms; their pain also impacted training. Participants often described completing their training as ‘doing their job’, or “it’s my job” (Liz), and accordingly, that endometriosis led to significant disturbances in their ‘employment’ or training. Participants described how their pain impacted their ability to perform their ‘job’, which included mainly training and racing for them as athletes. One participant framed this as “you never have any job security” when referring to constantly having to perform in sport. Chloe, for example, said:

I just stopped literally **I couldn't train on it** [referring to her period] I couldn't do anything **I think my body was in shock** because it didn't know what the pain was so everything tightened up around it but as the months went on the pain was unbearable.

In describing herself as “in shock,” Chloe explains the immobilisation of being in so much pain; this immobilisation led her to miss training when she was on her period. Participants often had to miss or modify training due to pain or endometriosis-related symptoms, including fatigue, heavy bleeding, or back pain. Taking time off work due to pain is common for women with endometriosis (Fourquet et al., 2010; Hansen et al., 2013). Similar to Andysz et al. (2018) and Gilmour et al. (2008), participants described how endometriosis was the cause of significant disturbances in their ‘employment’ or training. In contrast, some participants managed to continue training but explained how they had to persevere through severe pain. Ella described one experience as:

In the lead-up to surgery so I did a like 30k trail run over Christmas and then I couldn't run again **I had one of the worst symptoms** I had is this sensation that the space below my belly button and to the sides around to my hips it felt like that was trying to fall out. While Ella persevered through a thirty-kilometre training session, she then had to modify her training due to the ongoing pain experienced in this session.

Briar described how her training was impacted by her loss of motivation due to the pain: “I’d probably say I was finding through training that you will be **less motivated to train**, and sometimes I got to the point where **you actually couldn't train** because your cramps are so bad.” Even after being asked about her own experiences, Briar uses the term “you” here. This portrayed a tone where she generalised her experiences. In addition, Sofia, when asked about how endometriosis affected her training, said that she found herself getting stuck in a cycle of lying, missing training, and experiencing guilt:

It affected it heaps I just wouldn't train if I was bleeding **it would be too heavy too painful** but that could last three weeks at a time so I just wouldn't train for three weeks and then Dad would be like why aren't you training you need to go on your bike and I would just be like no I don't want to but **I didn't tell him why** because I didn't think...I hated it because I felt so guilty because I had this amazing coach and I wasn't doing what he was telling me to do **so I felt really guilty** for that hey if I told him he would have been fine with it but I just didn't think I could have.

Sofia described how she had many opportunities to speak up and noted that her coach may have been understanding. Still, she never felt comfortable bringing up how she felt as she said that talking about periods was ‘taboo’. The concept that women’s bodily functions are taboo has a long history. It creates pressure to repress thoughts and feelings explicitly related to the female

body as it has long been stigmatised as disruptive and unpredictable (Price & Shildrick, 1999; Shildrick & Price, 2017). Possibly due to this stigma, participants described a culture of 'not speaking up' and 'keeping their pain to themselves' to avoid being viewed as fragile. These descriptions of non-disclosure had similarities with Wilson et al. (2021), who found that when in pain, rowing athletes were afraid to be honest, due to fears of being viewed as weak.

While impacts on training were a burden, participants felt that the negative impacts on racing were the most significant. If they were unlucky enough to have an event fall on a day in their cycle where their pain was at its worst, they were physically and mentally impacted. Participants considered racing to be the most crucial part of their careers. Their results were often the basis of future funding and selection decisions, so their performance in racing ultimately defined the course of their careers. In addition, Sofia explained how her period would often come when she had an important race coming up:

It was always the biggest coincidence I was always bleeding when I was racing just always tired just couldn't do good like I'd been training fine the week before I start bleeding and then go terrible I just couldn't do it yeah it is affected it so much but it affected some competitions just in terms of I hadn't quite figured out like the pain management side and so if I had like a bad period and I didn't have any painkillers on me or anything then that wasn't very nice and so I probably that would then affect me mentally because you just when you're in pain or so or uncomfortable you don't necessarily like it's hard to feel mentally and at your best I thought yeah my whole immune system as well gets like it appears to be get really suppressed I mean everyone's does but my I'm quite sensitive and gets really suppressed and I don't if I don't sleep very

well so when I used to get sick a lot more as well which then obviously would take time out of training.

Sofia's quote illustrates how her endometriosis-related pain and symptoms would cause a cascade of events. Sofia described her embodied experience, which brings us to the root of human perception (Csordas & Harwood, 1994). Sofia described how she felt fine in her body during training, and then her body would "let her down" by getting her period at a crucial time. She described herself as "quite sensitive," bringing us into her embodied experience of being impacted by things like lack of sleep or stress. This demonstrates how in tune she was with her body as an athlete and a person with endometriosis. She also links her brain and her body, reflecting on the mental toll of this embodied sensitivity. For Sofia, keeping her experiences a secret took a mental toll, and she ultimately 'had to retire' from sport, as she considered the effects of endometriosis on her performance 'not worth it' when considering continuing.

### ***Subtheme Two: "It really really broke me": Impacts of Endometriosis on Mental Health***

Part of the burden of endometriosis for participants was the impact that they experienced mentally. The time-consuming and debilitating effects of having a disease, or the stress of not knowing what was wrong with them, took a toll. Participants described experiencing profound and intense symptoms, including depressed mood, diminished pleasure in everyday activities, fatigue, loss of energy, feelings of worthlessness and even recurrent thoughts of death. Participants described times when their pain made them feel "broken" and "depressed".

Participants also identified having thoughts of "being a burden" or "not wanting to be here" due to the suffering that endometriosis was causing them. Tiana described how the pain led her to "feeling crazy" and described some intrusive thoughts that resulted:

It's horrendous and especially when you're surrounded by it all the time and coming off the back of a really successful year it was horrible knowing that the other girls were cracking on with training getting PB'S [personal bests] it was really hard because I was living with rowers it broke me **it really really broke me** because I was just like I couldn't I couldn't do anything about it and that was the worst thing it wasn't like I could do something that I knew would make me better to then get back on the team and no matter how much I tried I'd get better for say two to three weeks and then I'd get pushed back again because of my period I think my body was in shock because it didn't know what the pain was so everything tightened up around it but as the months went on the pain was unbearable.

The “shock” Tiana describes experiencing in her body as a result of the pain impacted every facet of her life; this led her to question everything, including “the point” of life. She continued:

Because I was just sick of being in the pain to the point where you know lying in bed hurt lying down hurt walking hurt and I just remember it being so depressing in terms of not being able to do anything like not even being able to live a normal life let alone try and do the things I wanted to do it sounds like thoughts like are not related to having endometriosis but like in terms of like depressive thoughts I like became obsessed with the like you know one day the sun is going to explode I became like obsessed but and then I was starting to wonder what is the point and if it was and that was like my main thought process like pretty much every day for those four months and then like a lot of the time that was like combined with I never I never like suicidal thoughts but I spent a lot of my time during those months not wanting to be here but wasn't like I didn't want to be here I just didn't want anything to be here because life was exhausted me which again

was a combination of like this health stuff and the other stuff and it just was like too much.

Meanwhile, Tiana and other participants also described how they were under immense pressure to perform. Thus, while dealing with the exhaustion of “this health stuff and the other stuff” weighed heavily on participants like Tiana, they described how they constantly tried to balance their endometriosis while ‘mentally turning up’ for training and events. Sofia, when asked about how she felt about missing training, said:

Definitely **sad and um really frustrated** that I just couldn't go and train as much as my teammates were able to do um I know that I wasn't like faking it but I felt like oh well if I'm just messed up in my head why can't I go train five times a week yeah that definitely made me feel pretty shit **why can't you just be normal** but why did it have to happen like just be normal it just makes everything that much harder.

Sofia explains how she felt judged by her teammates that she was “faking”, which led to feelings of frustration where she just wished she was ‘normal’. Comparing herself to being “normal,” Sofia adopted the idea that she could be “just messed up in her head,” which was the narrative given to her by coaches and HCP and how the mental concerns compounded with the physical to make ‘everything harder’.

Dani, whose main symptom was pain during intercourse, identified how her sporting and personal identity often became intertwined and how her mental health was affected:

Your performance and identity it's quite hard sometimes to separate those two and so I always especially when I was young I struggled with feelings around like was I worthy of being able to do what I did and then because I was at times struggling with like intimate relationships as well it made it feel like it like I was the problem and so I think that then

impacted my well not really my performance but my perception of myself and what I could achieve in relation to performing because I had a lot more self-doubt there around me personally irrespective of my performance which then obviously transfers and translates over to your sport as well so I think yeah like when I look back at it definitely would have impacted that [mental health]...because I've got a heavier flow and then if I sometimes have cramps then it just makes me like eh like grumpy mood not grumpy but just you just feel a lot more shit... I think I got some PTSD [Post-Traumatic Stress Disorder] I'm pretty sure I had like I got PTSD from it and like it obviously not necessarily PTSD but like something along those lines that just really like until more recently I had to do a lot of work on myself to be comfortable.

Such intertwining of identity and sport can lead to mental health challenges when the sporting identity is threatened, for instance, through developing an illness (Xanthopoulos et al., 2020). As Dani described, endometriosis led to her struggling with feelings of reduced self-worth in general and in relation to her sport. She plays with labels like PTSD to make sense of her experience but ultimately notes “not necessarily PTSD but like something along those lines”, making space for self-exploration. This identity conflict is also known as biographical disruption, where the knowledge framework of everyday life is unsettled which unsettles worldviews of self, causing significant distress (Bury, 1982). For participants, this required them to reconsider their role in sport and life outside of sport and reconsider their concepts of self.

This intense focus on sport and the constant struggle surrounding endometriosis impacted participants' feelings of personal autonomy, which can be a risk factor for mental health issues (Cresswell & Eklund, 2007). Some participants described how they had been previously diagnosed with anxiety and depression; others were worried that they might be “depressed” due

to their experiences with endometriosis. As sport often implies that only mentally strong athletes are competitive (Markser, 2011), participants described how these feelings of burden and weakness discouraged them from speaking up about their mental struggles. Athletes experience similar mental health concerns to peers (Beable et al., 2017; Xanthopoulos et al., 2020). However women with endometriosis have higher rates of mental disorders and suicidal thoughts when compared to their peers (BBC, 2019; Sepulcri & do Amaral, 2009).

### ***Theme One Conclusion***

Overall, participants described severe impacts on their ability to live normally. There was particular emphasis on the effect pain had on sleep, training, racing, and mental health. The pain of endometriosis presented a burden like a rain cloud that impacted almost every area of their lives. This led to feelings of uncertainty, anxiety and conflicts with self-identity and affected participants' abilities to sleep, train and race optimally.



## **Theme Two: “How Was Your Holiday?” Experiences of Invalidation and Minimisation**

In addition to the burdens acknowledged in Theme One, participants experienced significant invalidation and patronising from not only those in positions of power who were meant to be supportive, like doctors and coaches, but also from friends and family. Minimising and self-invalidation compounded these experiences of invalidation.

In this theme, I explore how participants went from acknowledging their burdens to invalidating them. This happened both externally and internally. The load of these burdens was often not shared with many others. Participants kept their pain primarily to themselves or just a few trusted others, and when they did share, it was often met with scepticism rather than compassion, even by loved ones. Participants often disregarded their pain in an attempt to avoid ‘making excuses’, convinced themselves that what they were experiencing was normal, and lied to themselves or others about their experiences. While some participants had coaches who helped their athletes approach the problem directly, others had influential people exacerbate their efforts to minimise and normalise their pain. Participants described how their coaches, support staff, friends, family, and HCP were unhelpful in recognising their experiences as authentic and valid.

### ***Subtheme One: “Maybe I’m Making It All Up: Conflicts Between Embodied Experiences and Expertise***

Participants often described their experiences with Healthcare Practitioners (HCP) negatively. When seeing a doctor, participants felt ‘dismissed’, ‘not listened to’, as though the doctor thought they were being ‘dramatic’ and even questioned their own embodied experience, wondering if they were ‘going crazy’. Sofia stated, “I just thought because doctors I mean tell you when something's not right but I had four different doctors saying that I was fine I was like **oh my God maybe I’m making it all up**”. Sofia went to the doctor because she was

experiencing challenges, and receiving no tangible help meant she had to continue seeking other doctors. In Sofia's experience, HCP are framed as powerful and as though they provide expertise that trumps that of the patient. It makes sense that being shut down by the 'experts' negatively impacted her confidence in her own bodily experiences. Sofia's quote ends with "maybe I'm making it all up", which demonstrates the power of the HCP telling her she was *wrong*, not only in her words but in her experience of believing her body as being the bearer of truth.

A similar experience of second-guessing herself was described by Chloe who said:

It made me question myself and whether I was making it up and whether I was lying and it also made me think well they're the professionals and yeah so I managed to see a gynaecologist and he was like I don't think it is endo but will give you an internal examination internal scan see if we can see anything and no joke I must have had about five and every time they showed nothing and I was like the pain is still there I'm not making this up and it literally makes you feel so rubbish about yourself in terms of just am I just making this pain up is it my mind is it because I don't want to train and it was just so frustrating.

Participants regularly described experiences like these, where being dismissed led to feelings of pain being "in the mind" or, as Chloe explains, feeling like this was related to subconsciously not wanting to train. A part of the reason doctors' opinions may have been so salient in leading participants to question their own embodied knowledge may relate to the power doctors hold in this interaction and in general in society. Many doctors take the role of the 'expert' and bearer of authoritative knowledge when treating patients with endometriosis and often dismiss embodied experiences leading to feelings of invalidation and lowered self-esteem (Kool et al., 2013). Liz

described how she sought help during the ‘worst pain of her life’ and was sent off with only a prescription for paracetamol.

Participants often experienced a diminishing of their experiences from males in positions of power, including coaches and HCP. As with the majority of authoritative knowledge forms, medicine is often understood as ‘masculinised knowledge’ (Davis-Floyd & Sargent, 1997), and because men do not experience endometriosis for themselves, it seemed to participants that they could not relate to the experience, or have empathy for those suffering. This masculinised knowledge was held up as hierarchically superior to the participant’s own feminised embodied knowledge. While the HCP of most participants were male, masculinised knowledge appeared to influence female practitioners as well. For Alex, when opening up to males in positions of power, she was met with disrespect, invalidation, and patronising communication, which made her feel belittled:

I think he was like cardiac thoracic surgeon this was like when I was like going to get a laparoscopy and...he was like the most sexist like he was saying to me it just made me realize like he's just like he basically called my pain a belly ache and said like before I left was like oh yeah the truth is we can't cure everyone's belly ache erm and told me that I shouldn't get laparoscopy because what would it do and what else did he say also he asked me to describe my pain and I described how I just described to you [like I've been severely beaten up] and he said yeah he said all can you describe the pain and I said like it feels like internal bleeding it's like the worst pain I've ever had in my life and I think he wrote on the pain section on the form it was like bruising and then he started telling me that his daughter had it and just got on with it and I was like you just met me and I have no idea who your daughter is and I don't really give a shit he didn't help me and I came

out of that he was basically like yeah don't get laparoscopy it's not going to do any good if the medication's helping you just stay on it and at this point I have no idea like what it was still like I thought it was this but this guy was just like I don't know just like putting it to the side and so that was really frustrating and then I ended up being referred to him and...like even I've had quite a hard time like dealing with men who obviously have never experienced it and like just don't take it seriously and some of the stuff...yeah after that I was feeling like I was pretty upset and obviously as well it's scary because endometriosis can like range from mild to like life ruining and at the time I was reading stuff on like being infertile and like all this big scary stuff for them this guy was just like oh well just stay on medication and spend the rest of your life wondering whether that's that.

Considering that medicine is an evidence-based field where empirical studies are valued as 'the truth', it was interesting that this doctor used a person he knew, his daughter to generalise all women's experiences. Alex later summed up masculinised knowledge by later saying, following her diagnosis:

They found stage three endometriosis with deposits like in quite a lot of places and in the Pouch of Douglas [the area between the rectum and posterior wall of the uterus in females] which I had no idea what that was but I looked it up and I feel that just sums up everything I just said it's like a female body part named after a man.

For participants, this imbalance of knowledge contributed to a process of invalidation when their own experiences conflicted with healthcare provider interpretations. This finding has previously been reported in the literature (Burke, 2019). This often began with some diagnostic tests or investigations, followed by participants being informed that there was nothing wrong or there

was no diagnosis. Finally, whether it was stated directly by the HCP or not, participants often came to the only ‘logical conclusion’, which was ‘it must be all in my head’. Understandably, having conflicting accounts between their own bodily experiences and what the ‘expert’ HCP were saying led to feelings of extreme frustration and confusion.

These experiences of feeling dismissed and misunderstood have been described as invalidation and minimisation elsewhere. Two types of invalidation that are particularly relevant here are: discounting and lack of understanding (see also Witkowski, 2017). Discounting can be understood as denying, overprotecting, lecturing and patronising and lack of understanding has been conceptualised as providing a low level of acknowledgement and support (Witkowski, 2017). This occurred for Chloe when the HCP said to her, “I don't think it is endo but will give you an internal examination internal scan”, in a patronising manner. Instead of feeling supported, Chloe felt as though the HCP was not taking her concerns seriously. Participants also described a type of deception which occurred when there was some acknowledgement of a phenomenon or problem, but it was downplayed. This is known as minimisation (Guerrero et al., 2017). Sofia and Chloe described how they persevered to get answers, but by being minimised by HCP, they were led to believe that they could be making it up.

In addition, being invalidated and minimised also led Ella to question her own experiences and wonder if others were experiencing the same:

I've reflected back and my earlier symptoms were amenorrhea and irregular periods and phenomenal pain when I would have a bleed that I just thought was normal because everybody gets sore. I just wasn't able to hack it even though I was doing it. I was also doing the splits and somersaults and running a lot I think I thought it was just I couldn't hack all of that strenuous exercise with bleeding. I needed to get over it am I actually

making a big deal about something that's just not a problem like is everyone just walking around with this pain all the time and it's not bothering them.

Here Ella described how she doubted her ability, of whether she could “hack it” by assuming that others were going through the same thing. This process of normalising a negative experience as something that ‘every woman goes through’ is typical in women with endometriosis. Due to social stigma, women may stay silent on their suffering because they are led to believe that suffering is just an expected norm (Matías-González et al., 2021). This has been described by Jack and Dill (1992) as self-silencing, where participants avoid telling the truth about their experiences, or parts of it, to protect themselves and their relationships.

Being dismissed by HCP had enormous implications for participants. It meant that instead of being able to access the help they required promptly, they were forced to wait or seek out second, third, fourth, or more opinions. For some participants, this meant taking time out of training to travel lengthy distances to attend appointments, spending additional finances on medication or appointments, or being placed on long wait lists to see a specialist. This added an extra layer of burden to their suffering by prolonging it, creating significant delays in diagnosis and treatment, adding a mental toll. Receiving a correct diagnosis is critical for gaining insight into symptoms and is fundamental in accessing the correct treatment (Bontempo, 2021a); healthcare practitioner dismissal of participants appeared to be a barrier preventing this from occurring. This also discouraged participants from seeking more help or led them to wait until their pain was ‘unbearable’ before trying again to access care (see also Fawcett et al., 2020).

Being invalidated by healthcare practitioners and the subsequent delays participants experienced in both diagnosis and treatment was a practical issue but also an emotional one. Women with endometriosis who feel they have been invalidated and subsequently experienced

delays in diagnosis and treatment and non-specialised care often feel that HCP are not taking them seriously (Pettersson & Berterö, 2020). This issue is gendered and reflects the power dynamics illustrated above. Minimising female patient experiences can be linked to historical discourses of hysteria, which continue to be prevalent in modern medicine (Krebs & Schoenbauer, 2020). Patients who have an alternative theory to the doctor or those who find the suggested treatment unhelpful may be particularly likely to be labelled as “difficult” (Young et al. (2019). Gynaecologists, for instance, may be suspicious of the accuracy of women’s accounts and may, in their notes, find medical ways to validate them (Young et al. (2019). In so doing, women may be constructed as reproductive bodies rather than approached with appreciation and empathy in relation to their embodied experiences (Young et al., 2019). Instead of viewing the participants as experts of their own bodies, the authoritative knowledge approach of HCP perpetuated participants’ suffering. This happened for Aroha when what she felt and what she heard from the doctor did not align:

Because I had such a bad race I didn't want to make it seem like I was making an excuse and we want to be like oh yeah cool yeah like you were fine before that I'd been told by doctors that I was normal so they would have listened to the doctor because that's what the doctor was saying because they know what's wrong with you so I thought I was being dramatic.

Again, this statement reflects the power of healthcare provider expertise, where the athlete was not seen as the expert of their embodied experience, but instead, the doctor or HCP was viewed as the holder of authoritative knowledge. Patients may be taught also to invalidate their experiences when the narrative presented by healthcare providers is that their own bodily experiences cannot be trusted (Bontempo, 2021a). When Aroha’s experience did not align with

that of the doctors, the doctor's view was taken as the 'truth', and Aroha's experience was dismissed. This comment also identifies how Aroha ended up questioning her own experience by saying "I didn't want to make it seem like I was making an excuse".

***Subtheme Two: "I was exemplified because I pushed through" Influences of Coaches and Support Staff***

In addition to invalidation from HCP, participants felt invalidated by their coaches and support staff. When referring to the endometriosis pain in her diaphragm, Liz said, "Having to explain myself after a race like and they kept telling me it was anxiety and I was like it's not my throat is closed". Furthermore, Chloe's pain was invalidated and minimised time and time again by her coach and physio:

I had really bad back pain, and it was just pushed off as part of rowing and months went by and I still getting back pain and then they're like oh maybe it's actually just from like rowing maybe you know it's just tight so they gave me epidurals sclerosis injections but nothing seemed to be taken away the pain and I literally I stripped my training right back and every time I'd go to physio I'd either get shut down and they'd be like oh you know we think it's your back I don't think it's your period and I'm like I'm telling you it's my period like I'm on the middle of a training camp I've just had a period I'm now having another one and my back's hurting like when I was at home and I'd wake up with literally severe back pain in that lower right hand side and couldn't touch my toes couldn't do the side tests and I remember like even like trying to go to train and trying to walk through the door and not being able to do anything and you know sitting standing would all hurt and it's like why am I even here like I'm not gonna be able to do anything but I want to



show up I want to turn up and at the time the coach at the time made you feel like you oh he would say **how was your holiday** going like he'd be really patronising about it.

Chloe explains how instead of validating her embodied experience, the staff took the role of the expert and dismissed her concerns that her pain was related to her period. In addition, the coach was patronising towards her instead of being understanding. Chloe elaborated on how these attitudes began to influence her thoughts about her identity and sense of self. She continued:

He would make you feel really guilty for missing training I think that was really hard and it was like no one really understood what was going on and instead of tailoring the training to allow us to you know deal with these things like looking at the bigger picture erm it was like if you're missing the training then you're not good enough to be there so there was like a lot of pressure on myself to be there and to try and row but when your body is not letting you can't do it and then that mentally affects you because you feel like you're not good enough and you're a disappointment basically.

While, at times it can appear that athletes are complicit with dominant discourses from coaches because they agree with them, it is often because funding and selection are at stake (Lang, 2021). Athletes have been shown to comply with directives of coaches, even if they personally disagree with whether it is in their best interest or not, demonstrating the power imbalances (Lang, 2021). Here, although Chloe knew she would not be able to train at her normal capacity, she felt she 'had to' turn up to training because she had "no choice".

Considering that most sports staff are male and that sporting experiences typically occur in contexts where men and masculinity are favoured (Clarke et al., 2021; Norman, 2016) the additional gendered power imbalances can compound the issue of not being able to speak up. These power relations between the male coach and female athlete can create a sense of

vulnerability in sporting environments (de Haan & Norman, 2020). Female athletes may feel uncomfortable discussing things like their menstrual cycle with staff (Findlay et al. (2020). Participants in my study described that they were even less willing to discuss menstrual dysfunctions or pain with men. Sometimes when they did so, they would be unwillingly exemplified for dismissing their own experiences and held up as superior or inspirational for being able to push through the pain. Ella found that, at times, she could push through her pain and still complete training. She said:

I was **exemplified because I pushed through it** and I think that's a huge regret for me as I'm a person now who would not stand for that shit no no but at the time when you're being held up as like why can't you be more like Ella who just gets on with it.

Although exemplified, Ella still experienced minimisation. Expecting her to push through to be an example to others is a way her pain was invalidated. The need for comprehensive educational frameworks with goals to improve knowledge and practice around menstruation and related dysfunction in sport encourages collaboration and promotes effective communication and has been established in the literature (Clarke et al., 2021). However, only a few participants experienced open-mindedness and empathy from their support staff. Dani, for example, described how her coach was understanding and supportive of her:

I've always had a really good relationship with him and I think coming to him as a slightly older athlete as well and he didn't really get a choice and what I would talk to him about so I would just I would I'm very I'm quite an open person anyway and so I would just like talk about stuff and it was kind of maybe so for us yeah I'm fortunate that I felt really comfortable about talking to him about it and he's been really open like he'll send me a text and be like has 'it' [her menstrual cycle] come yet you know like you like

stuff like that then I don't have the pressure especially if I'm having I'm having really bad cramps I just don't have to worry about being like all I have to go to training and I've got to put on a brave like put on a brave face or worrying about leaking or anything like that, like I don't because there's no toilet at where we train.

While Dani's coach did 'take the pressure off' around performing when menstruating, Danielle reinforced that he did not have much choice in the matter. Whether participants were able to talk openly with their support staff appeared to rely on the confidence and assertiveness of the athlete, as opposed to the communication style of the coach.

### ***Subtheme Three: "You Just Need to Relax" Invalidation and Minimising from Friends and Family***

In addition to experiencing invalidation and minimisation from HCP and support staff, participants also experienced this when seeking support from their friends and whānau. Dani, when opening up to her family, was told that what she was going through was normal:

All this is normal this is just what women have to go through because that's what we got I remember my grandma saying that her sister every time she got her period every month she'd have to take like two days off school because she was so bad you know and then she's like oh that's just what happens it's normal.

This misunderstanding was perpetuated to Dani through her female family members. Previous generations may have experienced pain during menstruation and attributed this to "normal" period pain, so they may impress their views onto younger generations. It appears that, despite their own suffering, women who have had their pain dismissed by an older generation may continue to dismiss the younger generation. In addition, Aroha recalled her anger at her dyspareunia (pain during intercourse) being dismissed by her ex-partner:

I think it's really I mean this is getting very personal now but and I had I had one partner that it was really hard to explain that I was like no actually sometimes this is painful and they will say like no you just need to relax just relax I was like no you don't understand what this is like relaxing is not going to it it's not like I'm nervous it's like it I don't know it's almost like it's like bruised or something like I'm not gonna be able to just relax that way and that made me feel a bit like I was nuts like this is a very real feeling I feel like I'm not being understood whatsoever and yeah I probably felt a bit crazy then also nuts like I was like I was angry like listen to what I'm saying is not just a case of like I can yeah do a few yoga breaths.

Simply being told to relax was not helpful for Aroha and exacerbated the issue by making her feel like she was not only in pain, but also “nuts”. This relationship pressure took an additional toll on Aroha’s wellbeing. Aroha tried to explain what was happening, yet her partner was unsupportive in trying to understand her lived experiences. In addition, Aroha noted how she assumed that her friends had the same experiences:

It probably actually started a long time before I realised it did and like when I was in school I’d miss a lot of time for having period pains and which I kind of assumed as maybe more normal than it was because I’d tell my friends I’d had cold or something like that I wouldn't necessarily say I’m having three days off with my period and so I assume that when they said they had to cold that they also would also be having period pains.

Aroha explains that it was more socially acceptable to have a cold than to have period pains. This is an example of menstruation as a taboo topic that was avoided, even among friends (Chopra, 2020), demonstrating the surrounding stigma.

When women were trivialised by HCP, it was no surprise to participants that their family and friends also under-estimated the effects. In addition, there are also broader gendered dynamics and societal effects at play. Friends and family live in a world where women's pain is not taken seriously, and some may have had their own experiences of being dismissed. This dismissal is then internalised and used to interpret the experiences of others, perpetuating the cycle. Being invalidated by those meant to provide care and support often led participants to minimise and invalidate their own experiences, which often resulted in a reduction of self-esteem (see also Gambadauro et al., 2019). This invalidation led to self-silencing, which occurs when someone avoids saying what they think or feel to protect themselves (Jack & Dill, 1992). This was reinforced further by the 'expertise' of HCP who were trusted above participants and compounded by generational misunderstandings of women's pain. Feeling misunderstood not only by their doctor but also by the people that participants trusted made coping with endometriosis even harder (Grogan et al., 2018). Friends and family may have mistaken participant suffering as simply being in a bad mood or being 'dramatic', and participants even felt misunderstood by their partners (Facchin et al., 2018; Moradi et al., 2014). Dani explained:

Rather than seeing it as this is something it's like it's obvious and external this is just something that's happening with my body and this is how I can deal with it yeah I think that sometimes it's very easy to deal with when you've been diagnosed with it to think something's wrong with you and so...it used to feel like I was like it was just yeah there was something wrong with me I was the problem which obviously then impacts your staff listening and other things and then if I wasn't doing very well in my performance then I would again just had those negative thoughts that I was the problem, and it would just kind of feed off that.

### ***Theme Two Conclusion:***

Overall, Theme Two describes how participants embodied experiences were confused by the opinions of those whom they saw as support people or experts. Subtheme One explained the conflicts between the embodied experiences of participants and the information given by those in positions of power, causing them to consider that ‘it was all in their head’ or that they were making it up. Following this, participants explained how coaches and support staff influenced them to push through in Subtheme Two. Finally, in Subtheme Three, participants shared their disappointment in being invalidated even by their friends and family.

### **Theme Three: Recognising “Maybe This Isn’t Normal” Advocacy and Overcoming Barriers**

At some point in their journey, each participant reached a milestone where they felt ‘enough was enough’. Every participant experienced a significant event that led them to seek out more help and endeavour to receive a diagnosis. For many, this was only initiated by their suffering becoming unbearable and leaving them with ‘no choice’ but to find answers. All participants experienced a struggle to get diagnosed and felt frustrated as a result. For some participants, they had someone, usually, a family member or HCP, notice that something did not seem right and advocated on their behalf. Many participants described ‘that one person’ who was most influential in their journey to diagnosis and felt ‘if it was not for them’, they may have ‘never found the answer’ or may still be looking for one.

#### ***Subtheme One: “It Became Really Bad” How Invalidation Delayed Diagnosis***

Participants endured significant pain and suffering before either being able to, having the motivation to, or feeling validated enough, to seek more help. Participants believed that ‘some pain’ was normal or acceptable, but there was a ‘limit’. Tiana, for instance, indicated that some pain was acceptable by saying she went to seek more help when she noticed: “this feels like more pain than I probably should be in”. Here, Tiana reflects on her pain in relation to a level of pain that might be “normal”; however, she uses words like “probably,” and “should,” which indicates some hedging or perhaps not being entirely sure what an acceptable level of pain might be. Others used similar language to describe this experience; for instance, Aroha said: “I was probably around 19 or 20 [years old] I was like oh I don't know actually like this feels like more pain than I probably should be in”, again reflecting that some levels of pain are ‘ok’.

When participants experienced a higher than usual or higher than “normal” level of pain, it was often the spark for them to seek additional help. Briar noted that it was not until “it became really bad that’s when I went to the gynaecologist”; similarly, Alex waited until her pain was severe enough to warrant a trip to the emergency department to take more action. However, to reach out and seek more help, participants had to ‘rise above’ the invalidation and minimising, as described in Theme Two, from the influential people around them, including HCP, coaches and staff, friends and whānau, and even their partners. Participants expressed that they believed if they were ‘taken seriously’ from the beginning, they would not have had to suffer for so long (see also Grogan et al., 2018). For Dani, whose most significant symptom was dyspareunia (painful sex), this meant being “crippled over” for hours after sex before feeling as though her pain was valid:

I thought I could live like this but at the same time I wasn't living I couldn't do anything so **I knew that there was something wrong and it's only because I persevered that it changed** and once I started to realise that **it wasn't normal** and started to have like longer episodes after sex with during sex that were just really really sore that definitely makes you feel like there's something wrong with you because this is meant to be something that's enjoyable for you and for the person that you're having sex with and you're like failing at it basically... **being crippled over for two hours post having sex is not exactly normal.**

Dani explained how she was torn between believing what her doctors were telling her and feeling burdened by ‘not being able to live’. Dyspareunia took a toll on both her and her partner, which is common in relationships (Rea et al., 2020). Dani believed that it was only due to her ability to persevere in seeking answers that she ever received the correct diagnosis. She



experienced confusion between ‘knowing something is wrong’ and needing to develop the confidence to debate her condition with HCP and her partner.

Again, due to the compounding effects of women’s bodily functions being taboo and stigmatised and the invalidation from HCP, it is common for women to endure great wait times and see many practitioners before receiving a diagnosis (Grogan et al., 2018; Moradi et al., 2014). In addition, Briar said:

I think I put up with it for a few months, and then I was talking with one of my friends at university and she had mentioned how she was in the process of going through a gynaecologist but I thought oh there’s no way that I’d have it and my parents didn’t think it was possible either there was no family history or anything like that probably a few months into it maybe three or four months that I kind of got sick of it and after having a regular monthly period I **just couldn’t deal with anymore** so I went to a gynaecologist... and from there that's where sort of the whole process with them started. Briar noted how not having any family history of endometriosis led her to believe that she may not have endometriosis. While family history is a known risk factor, endometriosis is so often missed or misdiagnosed that it is not a reliable predictor of whether someone will be diagnosed (Chopra, 2020). This medical discourse had worked its way into participants’ experiences, causing confusion, particularly when they were invalidated by HCP. For Chloe, it was not until periods became more and more irregular and the pain was untreatable that she felt as though things were ‘bad enough’ to get more support:

I had a rehab program and I think I was the one that was noticing that my pain was starting about two days before I’d start my period and then my periods then became more and more irregular in terms of the every two weeks every six weeks like it was really up

and down but at the time I had the implant in so I previously hadn't had any periods and then all of a sudden I was getting them and really up and down...every time I'd go to physio **I'd get shut down** and be like oh you know we think it's your back and I'm like I'm telling you it's my period like I'm on the middle of a training camp I've just had a period I'm now having another one I'm like these don't cross over as much as they do and then when the physio would be asking about the pain you know like when you have muscle tightness and you can release it there was no way of releasing it like not even acupuncture yeah not even that was released in it and it was like literally like if your pelvis is like this [holding up hands in a circle] the pain was like in the inside of the pelvis and I wanted someone to stick with it and release it [pointing to the deepest part] but **nothing was working.**

Chloe observed that her pain was related to her period. This possibility was dismissed repeatedly despite trying to explain this pattern to staff. When her pain became untreatable by her physio, she decided to seek more help as she knew 'deep down' that her period and back pain were related, despite the 'experts' suggesting otherwise. Despite invalidation, participants continued to persevere with seeking help. For Chloe, this was despite feeling let down by the fact that all her efforts up until that point were fruitless and "nothing was working".

### ***Subtheme Two: "You Had to Be Your Own Doctor" Self-Advocacy***

Several participants took a scientific approach to investigating their symptoms. Many used smartphone applications (apps) or handwritten diaries to track and monitor their periods and symptoms in detail. These information logs helped them to see patterns of pain. Participants described this as having to 'be your own doctor' to find answers; these were tasks they took on

of their own volition in the absence of recognition and support from HCPs. Two participants, who were registered physios, explained their scientific approaches to getting answers. Ella said:

I was using Fitter Woman that tracking app that's when I started to notice there was a pattern repeating every month where there is a two-week period and then another five day period in my cycle when I was at like just lots of pain and I was really low mood-wise and I was really tired and there were other little symptoms that were cropping up as well like constant flare ups in my left hip and in my right SI [sacroiliac] joint and other things like that I had this kind of ignored for years and thought oh yeah it's just part of me I'm just a bit bust up after years of training and throwing myself at a crash pad [from competing in gymnastics] that totally makes sense and it wasn't until and it wasn't until oh sorry the nipple bleeding stuff started happening and I had started gathering the data and I went to my GP and she gave me a referral to get a breast ultrasound so I did that but didn't follow up anything with it but then went back to my GP in November of 2020 where I had almost a full year of this app and all this data and the worst pain that I've ever had that would get worse over Christmas and then lead up to surgery in February but in that November sort of early December point I went to my GP and said **something isn't right and I'm really afraid** we have done that breast ultrasound and I haven't spoken to her specialist and this is when they started to get really concerned and talk about cancer and very scary things.

Ella explained how the culture of dismissal from HCP caused her to downplay her own experiences until she felt as though she had enough scientific evidence to build a 'case', illustrating how sport experiences intersected with her dismissing her symptoms. Logging her menstrual cycle and related symptoms provided her with the type of evidence she felt was

required for HCP to take her concerns seriously. She explicitly felt the need to self-advocate and ‘speak the language’ of HCP to be validated. Using her knowledge of her embodied experience and physio expertise, she could objectively say that “**something isn’t right**” and be believed. In addition, Anna, who was also a physio, stated:

The only thing actually that made me think about endo was it when I was doing my high-intensity interval training and things I would get anterior shoulder pain on the right side and I know that trigger points in the diaphragm can refer up there.

Due to her expertise, Anna recognised that she might have diaphragmatic endometriosis (DE). In addition, Alex, when talking about her experience where her boyfriend had to call emergency services to seek help (see Theme One), described how she recognised that she might have DE before it was officially diagnosed based on her symptom profile:

Soon after that I got put on the contraceptive pill and just to stop my periods to see if see if it would help to basically see if it was endometriosis but the doctors were still like it’s super rare to have in your diaphragm it’s probably not but then I had like scans and like my ovaries were fine and then they’re like oh yeah it’s really like it’s really not common for it to just be in your diaphragm but this whole time...but like **I knew it was that**.

Participants, even those without specialised training like the physiotherapists above, presented as experts of endometriosis. Many described sentiments of knowing more than their HCP about the disease and understood signs, symptom management, managing their energy, training and pain relief (see also Grogan et al., 2018; Seear, 2009).

Considering that the prevalence of endometriosis is higher than many other well-known diseases (Chopra, 2020), it was disappointing for participants to realise that they often felt they knew more about it than their HCP. This sentiment of having to ‘be their own doctor’ placed

additional pressure on participants. Many reported concerns with medications they were taking to combat their pain due to the unknown effects on performance and the strict drug testing rules they were subjected to. Participants were often prescribed heavy painkillers, including some that may be subject to bans by the World Anti-Doping Agency, the governing body for drug testing in sports (WADA, 2021a). Participants also described reluctance to take some medications, including hormonal contraceptives, due to their potential side effects on their performance.

This pressure to ‘figure everything out’ added additional stress on participants who described having to strongly advocate for themselves or rely on someone else to advocate for them to make any progress with their condition or be believed. Chloe explained how she felt she knew what was wrong and had to convince doctors to diagnose her.

I was literally like I was basically **begging them for a laparoscopy** and yeah they were able to give me one it took a while but I was able to get one and even then they were like you know we might go in and we might not find anything.

Even though the HCP had agreed to complete the laparoscopic surgery to see whether Chloe had endometriosis or not, Chloe felt that she had to continue to advocate for herself, to be able to prove that she knew something was going on. Despite this self-advocacy, the reception from the HCP was dismissive and invalidating. Instead of being supportive, the HCP patronised Chloe and said that she could be wrong and that they may not find anything.

During the interviews, participants often shared what they had learned and what their advice would have been to themselves and others. A diagnosis allowed participants to feel more educated about themselves and better prepared to help others. They encouraged others to strongly advocate for themselves, seek a second opinion and be prepared in training for all eventualities, including bleeding and pain. Participants mainly wanted to publicly dispel

misinformation and myths to peers, especially on social media Fields (see also Fernley, 2021).

Aroha said:

Try yeah keep notes and take those notes for appointments because the appointments are so short I think to kind of like arm yourself with more knowledge is really useful and but I want to say like spend more time researching but I didn't know that existed to research it and Google was coming up with some horrifying things that didn't really help so yeah I say that like **keep advocating for yourself** and I think the most important thing that could have could have like sped up my diagnosis would have been I would have been that like just keeping notes and going into every appointment knowing more about what I wanted to get out of it and being able to say like look I've had this this this and this test I think need to look into this this this and this or something like that and be a bit more a bit less passive I mean yeah I'd say like I advocated myself really really hard to get into appointments and specialist.

While Aroha states that being armed with the correct information was helpful, she also warned that searching for answers online brought up unhelpful diagnoses. Aroha stressed that instead of only having knowledge online, being prepared in appointments with historical notes was the most helpful advice she could give.

### ***Subtheme Three: “The First One That Actually Believes Me” How One Person Made a Difference***

During their journey to diagnosis, participants described how they finally had someone ‘make a difference’ or understand them. They often met with many HCP before finding ‘the one’ who helped. After Alex’s experience with the ‘sexist’ and patronising surgeon, she finally found someone who ‘took her seriously’:

And then they got me referred to the specialist gynaecologist and he was great he was like **took me seriously** and we chatted through the images where they show the growth and his like review of the meeting letter said a laparoscopy is absolutely necessary and like that's two like medical opinions that have disagreed at each end of the spectrum which is like crazy.

While relieved that someone was finally able to help, Alex explained her frustrations with the inconsistency of care. After presenting to two physicians with the same symptoms, one dismissed them as something she just needed to 'get over' while the other took immediate action. Sofia had a similar experience where she saw "four doctors from four different medical practices" and presented with the same symptoms each time. It was not until she confided with a family member that she sought out the final doctor privately, who was able to help.

My mum's a pharmacist so I came to her and I was like oh don't you hate it when like your period lasts like 3 months and she was like hmm **no that's not normal** so I kind of explained to her what was happening and she was like **this isn't normal** when you go see someone privately about this so at least if it is normal he can tell us we've come on to the best and he knows yeah so pretty much her saying that I wasn't like crazy um like listening was good.

Sofia's mother advocated for her to receive private care. Sofia described that her mother, as a pharmacist, was more equipped to get her the right help than the other doctors she had already seen who dismissed her concerns. When Sofia finally saw a doctor privately, she explained:

He looked at me he was like I'm 99% sure you've got it [referring to endometriosis] and if you don't have it then something's not right and will fix it together okay I'm not so crazy but here is the **first one that actually believes me that I wasn't being crazy.**

Sofia described how this was a huge relief to be believed and taken seriously. This doctor went on to organise laparoscopic surgery, where Sofia was officially diagnosed.

Chloe described similar sentiments when she described the doctor who made a difference; she said about the doctor, “**she was the one**”. Similarly, Ella illustrated the impact her GP made:

I felt really grateful to be in [the city she lives in] and have a GP who's got a background in ob-gyn [obstetrics and gynaecology] who I never I felt like **she never assumed anything about me** and spoke about pain in a way that was **related to my body** I wasn't like has a gingerbread man point to where the pain is I know I'd had kind of experiences previously which I was I was really shocked by that and reassured about it and I wasn't expecting the specialist to call me at 9 p.m. at night to talk on the phone for 45 minutes after I had scans that day.

Ella described how instead of objectifying her body and “pointing to it like a gingerbread man”, as she had experienced in the past, her doctor took her embodied experience as the truth. Ella explained how her doctor exceeded her expectations by calling her on the same day and providing adequate time to answer her questions. In Ella’s experience, doctors usually did not provide this level of ‘empathy’ and ‘care’, so this shocked her.

### ***Theme Three Conclusion***

In Theme Three, participants explained how the attitudes of HCP impacted the outcomes of the surgery by creating continued delays. Participants felt they had to advocate for themselves or bring ‘scientific evidence’ to be believed. Participants then explained how one person finally made a difference by validating their experiencing and advocating for their needs. Overall, Theme Three illustrates how attitudes of HCP made a significant impact on their journey.



#### **Theme Four: “Thank God I’ve got an answer” Misdiagnoses and Treatments**

Following the self or external advocacy participants described in Theme Three, participants went on to seek more support. However, during the process of doing so, they experienced many barriers. Subtheme One describes how participants were again minimised and invalidated and told to “just deal with it”. Participants described that they had few choices in accessing care, that appointments were challenging to attend, and when they did so, they were misdiagnosed. Subtheme Two describes how, eventually participants did get surgery and how feelings of relief were tainted by other fears.

##### ***Subtheme One: “Just deal with it” Poor Options, Lack of Accessibility and Misdiagnoses***

Once participants had established that there was something likely to be wrong, they faced many barriers in the pursuit of getting the right help. Firstly, participants shared how even simple tasks, such as attending appointments, were challenging due to the pain and fatigue they were experiencing. Chloe explained:

What was worse is that I was having to get the train from...where I was living at the time into town every time for an appointment on my own to go and see a doctor who would be like yeah we can't find nothing there's nothing wrong with you to get back on the train and go home and then not be able to train when my housemates were training on the team every day.

Chloe described the logistical challenges of getting a train to go to an appointment where she wasn't listened to and then how returning home was arduous and a burden. This left her feeling excluded as she would have to miss training while her teammates continued to train. The burden of her pain compounded with the mental exhaustion of being answer-less even though she was going out of her way to get help. In addition, when participants received treatment, they

described feelings of frustration with the options available. Many participants found that their HCP only focused on the physical components; for instance, Dani said:

Some of the psychological things that come can come alongside endo I think that there's definitely **not a lot of access** to like certain forms of treatment like for me it was I probably needed to have well I would have been nice you know if you had like some funded or even low cost physio women's health physio appointments or even access to you know if they mentioned anything about access to seeing a counsellor or psychologist there was just nothing like that it was just purely treated as a physical and...since then I they basically they put me on they gave me the option of going on I could have a Mirena [a hormonal contraceptive IUD (intra-uterine device)] or going on a pill and I don't like that this is personal but I just don't like **the idea of having something in my body that I can't control.**

Dani adds that losing control of her own body was an added burden. As Dani describes, while she could access *some* kinds of treatment, these were not necessarily the most effective or desirable, explicitly mentioning how it would have been helpful to have access to counselling or psychologists. Dani also refers to the psychological burden of both endometriosis and the challenges of trying to get help. In this quote, Dani also explores how the options offered to her, such as the Mirena or a pill, were not appealing as they make her feel out of control of her own body. Given the degree to which participants lacked control over the whole help-seeking process, this is notable—for participants like Dani, being able to be involved in and in control of their bodies seemed to be an essential part of healing. Dani's words about feeling out of control are particularly consequential in light of the stories as a whole. In addition, participants were

weighed down with misdiagnoses, leading to treatment for the wrong issues, which is common for women with endometriosis (Bulletti et al., 2010).

Participants were diagnosed with conditions including nerve irritation, back pain, pelvic inflammatory disease, and even sexually transmitted infections (STI). When asked about getting a diagnosis, Aroha explained that:

Then and most of them assumed as I had an STI so I cannot tell you how many STD [sexually transmitted disease] tests I had in that time and I'd be like I literally had one last week or last month or something and they would say oh well have you got the notes from it and I'd be like oh no I didn't bring them with me and then I'll have to do that again then and that basically would be the whole appointment so I think it like looking back I wish I just kept a folder or something on a case through my notes I could have gone in and said look this is what I've already done you need to go off this not just repeat shit that's already happened and I was also I was diagnosed with and I can't remember the name now pelvic inflammatory disease does that sound like a thing which is basically what I think what you get if you like had an untreated STI for a really really long time and I think you can get it otherwise I think that's the main cause is my very vague memory of it and so I was diagnosed with that for a little while and given a lot of antibiotics which again didn't really help my performance or training or anything and they just did nothing and obviously because I didn't have it and so that's was a bit frustrating that afterwards I was like look this didn't work and they were like oh but you have this disease and that's the treatments it must have worked and I was like well it didn't it didn't work and so I went through I think maybe two courses of antibiotics with that and that was like early 2018 things are probably about two or three months before I

got diagnosed and so yeah I went to a lot of different doctors who all assume that it was something and STI related until I went to the one who did my surgery.

Despite multiple negative tests, Aroha's doctors continued to be adamant that she had an STI. Aroha's experience highlights the gendered assumptions of not trusting women as patients as they are viewed as emotional and continue to be stereotyped as hysterical, despite advances in medicine which show this is not the case (Krebs & Schoenbauer, 2020; Young et al., 2019). Aroha's experiences are similar to those in Theme Two, where participants had to provide 'scientific evidence' as proof to be believed. As Aroha was rushing from trainings to appointments, being expected to provide test results that Aroha believed the HCP would likely already have access to was an added burden.

Participants endured ineffective treatments due to these misdiagnoses. Some of these were particularly burdensome and disruptive to their training and everyday lives, including nerve blockers, acupuncture, epidurals, induced menopause, antibiotics, pharmaceutical medications including hormonal contraceptives and pain killers and intrauterine devices. Despite sharing that they knew these would not work, participants often complied with trying new treatments out of 'desperation' or with small hopes that they would be effective. Anna said:

So um yeah so the first treatment I had was the **ilioinguinal nerve blocker** because I think initially my gynaecologist thought that it might just be an irritation of the nerve that was making it spasm but that didn't help so the next time I went to see him he was like well I was like you know what are my options he was like well either we do a laparoscopy or you **just deal with it as it is**.

Anna felt as though there were no good options. Being told to "deal with it as it is" felt discourteous as being at this appointment in the first place implied that she could not simply

“deal with it as it is”. The other option of having surgery was also not a desired option due to the time required to take off training for preparation and recovery from surgery and the fact that these periods were unknown. However, Anna reinforced that she would do whatever it takes as she felt she could not continue on the same path.

Considering that some of these treatments have severe side effects, it shows how motivated participants were to seek relief, knowing that the side effects may impact their training and performance. Chloe said:

I had **acupuncture** yeah not even that was releasing it...I was tight so they gave me epidurals injections but nothing seemed to be taken away the pain and I literally I stripped my training right back yeah so we took the implant off and they tried me on a pill to see if that would help my periods get back into a normal flow but rather than actually sort the pain out what else did we use I mean that was it mainly and because obviously being an athlete they were mostly just telling me to rest or cross train and that's not really I mean I couldn't I couldn't train for ages and I was just like they put me on a pill and that didn't work and I didn't respond very well and he was like okay let's try and reset everything so he put me on the injection to give me the temporary menopause and with that you obviously have to take an oestrogen gel because I was taking it more than three months or whatever the minimum is and the gel wasn't working so I had a patch and that was much better but it's quite a lot for your body to go through with like having the hot flushes having to have the injections in themselves whilst trying to train because at that point I was able to then train after putting myself through a temporary menopause when I know that these injections do have a side effect and increase your risk of cancer.

Chloe explains how she ‘tried everything’ to get relief, but nothing worked. Chloe explains everything she had lost and how hard the experience was for her. It was not until finally having surgery that Chloe and other participants had any significant relief from their pain which is common for women with endometriosis (see also Wulschleger et al., 2015).

***Subtheme Two: “Thank God I’ve got an answer” The Impacts of Surgery.***

When participants finally were able to access a laparoscopy, they shared feelings of nervousness, apprehension, ‘worry that it would not work’ or that ‘they wouldn’t find anything’, leaving no option but things being ‘all in their head’. This was possibly because participants had tried so many things that did not work and had been dismissed. Accordingly, it seems reasonable that participants would feel apprehensive about the situation. Few participants knew anyone who had experienced this surgery, and very few knew of other athletes who had experienced it. This led to additional worry about the surgery's implications on their training and performance. Participants found that recovery guidelines were vague and did not account for returning to significant training.

Participants all had laparoscopic surgery where endometriosis was removed by excision, ablation, or both. Some participants described that the surgeon was able to remove all endometriosis, but others, including Anna, had growths in hard-to-reach areas such as the diaphragm:

So that's what I said, right let's see do the laparoscopy and so went into surgery and they removed adhesions from I think I had a couple down around ovaries but not much and then the main bulk of it was large intestine so they chopped all that off and then the ones around my diaphragm he didn't want to chop because he didn't want to damage the diaphragm so they burnt it [ablation] and so yeah so kind of came out of that and he

basically said that he thought that he got it all but wasn't 100% sure because the diaphragm you can't see all the way around it because of where they go in and he said if it does come back or there's more up there it would involve more kind of open surgery.

Immediately upon waking from surgery, participants felt dazed and experienced confusion. They described that, while feeling like this, HCP disseminated important information, which they later realised they had forgotten or were confused about. Ella said:

That's my one piece of feedback I guess on the whole process was please don't tell me that I need to book and schedule follow up ultrasounds when I am just out of surgery with a heart rate of 18 after a complicated surgery and I'm out of it that's not the time to do that.

Ella explained how she felt that it was unprofessional for HCP to deliver critical information to her while she was not in a state to process it. Participants felt that the information they were given following surgery could have been disseminated more effectively (see also Grogan et al., 2018). While still under the influence of powerful surgery-related pharmaceutical medications, participants were given instructions for recovery, medication information and advice. Some participants had a support person present to relay this information later, but many were alone.

Participants also shared their reactions to having a confirmed diagnosis of endometriosis. These reactions were often positive and centred on feelings of relief that they 'weren't crazy'. Sofia said: "I felt so relieved I was like thank God I've got an answer". After being trivialised for so long by HCP, coaches, family and others, participants described feelings of validation and legitimisation (see also Cole et al., 2021). Alex stated that after finding an "eight-millimetre growth on my diaphragm" she felt as though this was "good news in a way because I knew that my pain was like legitimised". While it seems interesting that participants felt relieved when

being diagnosed with such a disease, it also makes sense as it is a diagnosis that they fought for so long. After surgery, Ella was informed by her surgeon, who said “I can confirm it's endometriosis I will call you to let you know it's not cancer”, and Ella, after digesting these “big statements”, said “I remember feeling just so relieved that those are the statements I was hearing, and it wasn't it wasn't anything malicious”. In Ella’s comments, she reveals being relieved by knowing that it was not cancer, as she considered that endometriosis was not malicious. She presents a hierarchy where endometriosis is not viewed as severely as cancer and described feelings of relief.

Similarly, Tiana described how she felt validated that she had a real condition: “I actually felt relieved because if I didn't have endometriosis then we are back to square one”. These feelings of relief that participants shared were, however conflicted by other emotions. For example, Briar said: “for him [the surgeon] to confirm that and then show me the photos post operation was definitely a relief but it was kind of like oh how do I deal with that from now on”. In addition, Dani shared that she experienced “a little bit of relief...but also scared because you have no idea what it what it's going to look like in the future”. The relief of understanding what the problem was mixed with feelings of devastation of being diagnosed with a life-long incurable illness. In addition, Anna shared how she felt initial relief but how these feelings quickly eroded when she began to experience pain again:

And because initially when I came out of surgery **I was literally buzzing** because I was like yes they found something you know I felt like this **weight had been lifted off my shoulders** and I literally for a couple of weeks even though I had the wounds I was just like oh I just felt so good and at the time I didn't have any of my normal pain so I was like yes it’s worked and I was just so excited and then I think it was about a week or two



later I had a flare up and I was like oh fuck um but I wasn't sure at that point whether I just overdone it with my return to sport.

Anna shared how she experienced emotional highs and lows, ranging from being “literally buzzing” and having a weight off her shoulders to thinking “oh fuck” where she began to doubt whether the surgery was successful or if she had overdone her training. Considering that return to training guidelines were highly vague, ranging from “just see how you go” to advising no training for weeks, participants felt confused as to whether it was them making the wrong choices during recovery or if the surgery had been ineffective.

Following surgery, participants underestimated the effects and how long recovery would take. Briar explained when asked about healing afterwards that “it was pretty excruciating and I think I just completely underestimated keyhole surgery and thought it was only a small female procedure”. While recovery often took longer than expected, participants felt it did provide significant relief to their symptoms and noticed improvements in their performances. Anna, who had endometriosis on her diaphragm, said:

And I noticed that especially one thing actually my partner mentioned after my surgery like I used to get out of breath quite quickly and just walking up a hill and for someone who's quite fit like you shouldn't get out of breath just walking up a hill but after surgery I didn't get that anymore so that was one kind of big tick for me but when I'm in a flare up I do get out of breath a lot more.

While Anna noticed that surgery had made a difference in her breathing, she also explained how the surgery had not wholly resolved her breathing issues when she got her period. Due to not experiencing complete relief, participants were often worried that they might need another surgery in the future. Aroha also stated how surgery did not remove all her issues:

Um pretty satisfied **it certainly didn't just solve everything** like I still got pain but yeah like I said it just the duration of time with so much shorter I wasn't just writing off a moment of my life here and there and just being in pain is kind of yeah I just it just became a lot more manageable and yeah felt like I kind of **got my life back a bit**.

Aroha described how her surgery did not “solve everything”, implying that she expected that surgery may have been a solution. Considering how long Aroha was seeking a diagnosis and how many treatments she was administered for issues that were, in fact, unrelated, it is particularly interesting that she hoped surgery would be a solution. On the other hand, Anna seemed to have lower expectations of surgery:

I would say I'm probably back to training as much as I ever was but it's still there definitely not as bad as it was um I guess when I do get a flare up it's probably less intense but it seems to last longer yeah exactly and it's not enough to stop me doing anything I can train through it I can do everything I want to do but it's just annoying one of those like low grade niggly just go away type pains and it definitely limits me I guess in what I feel like doing... or is it just a matter of living with what I've got and managing it and because at the minute I guess I feel like I could live with it as it is if I know it's not going to get any worse because if I know that I can deal with that so it's not only I guess that feeling of the unknown but also the feeling that **nobody can help you** you've been to see the best people in they don't know and so that was kind of just a bit frustrating and scary just the fact that is this just something that you're never going to know and you just have to live with and then you don't know if you don't know what it is you can't deal with it.

Anna appeared grateful that she experienced some improvements to her condition following surgery. This meant that she could consistently train, which was a noticeable difference. Anna noted that the relief for her was not only physical but mental. She described how the feeling of the unknown and that “nobody can help you” was an additional burden that was relieved from receiving her diagnosis. For Anna, simply having the knowledge of the problem made her feel more equipped to deal with it.

Following surgery, participants shared their concerns about the future. Many were worried about what ‘maintenance’ of their condition would entail and whether they would need future surgeries. Liz shared her concerns about having to remain on the contraceptive pill to reduce the likelihood of the growth of new endometriosis:

As a 24 year old there's a lot of others out there who are in a much worse condition with endometriosis or with anything else so I'm trying to think about that but it's um I think what I find hard is a lot of doctors didn't seem to care about the period thing and I also have like I'm a bit concerned about being on the pill for the next however many years because like the reality is we don't have any long term studies on how the pill affects women when they're older because the medication and we are on didn't exist like it's only existed for the past I don't know how long but not long enough you know and I've always been I've had suffered from mental health problems and I know that one of the side effects from being on the pill is like mental health stuff so I'm a bit worried but I'm not worried but like I just know that becomes like thing I have to be more conscious of and also yeah it's just I don't know I'm super anti anti-pills if I can help it so having to like get up and take something every day I don't like him yeah I don't like the compromise it feels like a big compromise rather than a solution which is hard.

Liz first compared herself to others acknowledging her gratitude of not being in a worse situation but continued to share her concerns about the future. Liz acknowledged the lack of research on hormonal contraceptives and how her mental health could be at risk due to side effects. Liz and other participants described a sense of ‘doom’ that it may always impact them no matter how positively they approached their condition. While they understood that they had received the ‘gold standard’ of treatment, participants were also aware that many still suffer after surgery, and many are put on contraceptive pharmaceuticals to inhibit future growth of endometriosis (see also Chopra, 2020). While this may seem confusing that endometriosis can still cause pain after removal, research has shown this may be due to central sensitisation, where nerves exhibit increased responsiveness and hypersensitivity (Nijs et al., 2019; Zheng et al., 2019). Additionally, participants were worried how endometriosis might affect them in the future and shared concerns about their future pay, selectability or even considered retirement due to endometriosis.

Participants found the return to training and competition difficult due to mixed messaging from HCP and other advisors and a lack of guidelines specific to athletes. Instead of having clear direction from HCP, participants shared how they ‘listened to their body’, ‘took it slowly’ or, for some, rushed back too soon and had to take more time off. Anna, for example, shared her return to sport:

I just started with a few short dog walks 15-20min...then I think by the end of that first week I got my turbo trainer actually my wind trainer on the bike and just kind of sat and just spin the legs for half an hour I wasn't pushing or doing anything silly and so end of the first week I think I was probably spending on the bike for about half an hour and maybe go into 45 minutes walks just on the level nice and easy nothing crazy haha and

then the second week I think I genuinely felt really good I think I was supposed to have two weeks off work but I ended up going back after 10 days because I felt absolutely fine and I just started on a few reduced hours and so I didn't have to work quite so hard and another thing I tried to go kayaking 10 days post op which was definitely too soon after about 20 minutes and I was like yeah I'm sore now.

Once fully recovered, participants shared how they changed their approach to training after their surgery, with a goal of being better at 'listening to their body' and avoiding 'beating themselves up' on bad days. The focus for participants moved towards using their cycle to their advantage and resting when appropriate. Participants shared how they noticed significant improvements in their performance, not only from surgery but training 'smarter' by 'understanding their body better'. Dani explained how her coach was on board with this approach:

We yeah **we do all my training around my cycle so which is pretty cool** the first day of my cycle so the first day of my period off training so whenever that falls I just have that off just to allow me to chill out and **not have to worry about any extra stresses** on my body and what else do I do I try and increase and from probably day two to three probably day three onwards and for the next two weeks I'm good to go and I just like can smash everything and anything and so we do my double I do a lot of double day sessions in that time and we really just like smash me for those and then I get to do kind of whatever I want like I get like a few days where I just do a little bit of we kind of scale back on all the on the challenging work and just do more of attempts some more technical work sometimes it's pretty mentally frustrating but I actually find that physically I can learn quite a lot in that time and then I have for the remainder of my cycle I'm probably not getting my timings right but around the for the remainder of my cycle I can do

whatever I want so I have free reign over that so this morning I'm in there at the moment, so I went to the gym this morning and I just finished off the session that I didn't finish on Monday.

Dani, like some other participants, explained how she had a 'breakthrough' by working her training in with her cycle instead of constantly trying to fight it. By structuring her training around her menstrual cycle, she observed noticeable improvements in her performance and mentally felt better being able to rest on the bad days rather than battling on and 'beating a dead horse'. Interestingly, significant research has been completed in recent years to evidence these effects (see also Carmichael et al., 2021).

Research on women in sport is generally rare due to the complexities of sociocultural marginalisation in women's health and the fluctuations of hormones during the menstrual cycle (Emmonds et al., 2019; see also Sims & Heather, 2018). However, a small movement of female athlete research is underway, which has evidenced that structuring training based on the menstrual cycle improves performance and reduces the risk of injuries (Carmichael et al., 2021; Janse de Jonge, 2003; Martin et al., 2021). The mental effects of these methods are yet to be established in the research, but Dani and other participants described positive effects.

#### ***Theme Four Conclusion***

This theme detailed how participant's experienced a lack of options and accessibility when seeking help for endometriosis. These experiences significantly added to the burden that participants experienced. Participants then described feelings of relief when finally receiving a diagnosis followed by feelings of apprehension about the future. Participants also shared how they changed their approaches to sport following their diagnosis.

## **Conclusion of Findings Chapter**

In conclusion of this chapter, I provide a summary of the key findings. Firstly, in Theme One, participants described endometriosis-related burden in a way that I likened to a rain cloud that precipitated on every part of their story, including their physical and mental health. The overarching burden of this was pain. Participants described how they experienced chronic pelvic pain (CPP), which was, at times, considered the worst pain of their lives. For many, this pain was debilitating and impacted their relationships with others and daily functions, including training and sleep. Participants described how the pain and subsequent fatigue reduced their motivation at times and made them worry about their future in sport.

As athletes, participants went to great lengths to conceal their pain due to fears of being seen as weak, which is a stereotypically negative female trait, and due to the taboo that continues to exist around menstruation (see also Cole et al., 2021; Price & Shildrick, 1999; Shildrick & Price, 2017). Additionally, the time-consuming and debilitating effects of having a disease, or the stress of not knowing what was wrong with them, took a toll on their mental health. The intertwining of sport and identity was illustrated when participants found that their sporting life was negatively impacted by endometriosis. Participants described experiencing depressed mood, diminished pleasure in everyday activities, fatigue, loss of energy, feelings of worthlessness and even recurrent thoughts of death alongside the feelings of pressure to perform. Some participants described how they had been diagnosed with disorders including anxiety and depression; others were worried that they might be “depressed” due to their experiences with endometriosis.

In Theme Two, participants described how they were often invalidated and minimised by those around them. Participants experienced this from HCP, which conflicted between the

participants' embodied experiences and the HCP's expertise. Participants experienced a phenomenon where doctors often take the role of 'expert' and bearer of authoritative knowledge and dismiss embodied experiences (Kool et al., 2013). This phenomenon is likely linked to historical discourses of hysteria, which continue to be prevalent in modern medicine (Jones, 2015). This experience led to feelings of being 'dismissed', 'not listened to' or as though the doctor thought they were being 'dramatic'. This dismissal led to delays in accessing help and forced participants to seek out second, third, fourth, or more, opinions from other practitioners.

Not only did minimising and invalidation occur with HCP, but participants also described how it occurred with coaches, support staff, friends, and family. Whether participants could be honest with those around them often relied on their own confidence and assertiveness, as opposed to the openness and acceptance of others. Participants illustrated how power relations between their male coach and them as a female athlete created a sense of vulnerability (see also de Haan & Norman, 2020). While it appeared that participants were complicit with dominant discourses from coaches because they agreed with them, it was often because funding and selection were at stake (see also Lang, 2021). Additionally, participants detailed the struggles they experienced in being invalidated and minimised by their friends and family.

Theme Three described how participants reached a turning point in their journey by realising that their experiences were not normal. This theme detailed why this took so long and the self-advocacy and one influential person required to achieve substantial change. Being invalidated contributed to delays in receiving a diagnosis.

Participants felt they needed to advocate for themselves and 'be their own doctor'. Some took a scientific approach to investigating their symptoms, logging, and documenting information. This pressure to 'figure everything out' for themselves added additional stress.



However, eventually, participants found one person who made a difference. Participants explained that somewhere on their journey, they connected with ‘that one person’ who took their concerns seriously and advocated for them to receive more assistance.

In Theme Four, participants described the difficulties they experienced in seeking help. They experienced poor accessibility when seeking support and felt frustrated and burdened by the fatigue and pain they experienced which made small tasks, such as attending medical appointments, extra challenging. To make matters worse, participants were incorrectly diagnosed with conditions including nerve irritation, back pain, pelvic inflammatory disease, and even sexually transmitted infections (STI) and subsequently endured ineffective treatments due to these misdiagnoses.

However, following these experiences, all participants finally got diagnosed with endometriosis and received surgery. Participants described nervousness, apprehension and ‘worry that it would not work’ or that ‘they wouldn’t find anything’, leaving no option but things being ‘all in their head’ before surgery. Immediately upon waking from surgery, participants felt dazed and experienced confusion. However, shortly after this, participants were informed of a confirmed diagnosis of endometriosis. Responses to this were positive and centred on feelings of validation and relief that they ‘weren’t crazy’.

After surgery, participants underestimated the negative effects, how long recovery would take and realised that surgery did not completely cure them, leaving them concerned about their future in sport. Participants portrayed the mixed messages they received regarding advice on returning to sport and noted the lack of guidelines specific to athletes. Finally, participants shared how their approach to training had changed following their diagnosis. Participants described changes in being better at ‘listening to their body’ where they began to train with their menstrual

cycle. Overall, this theme detailed how participant's experienced a lack of options and accessibility when seeking help for endometriosis, the related burden, and feelings following receiving a diagnosis.

## **Chapter Five: Conclusion**

The final section of this thesis outlines implications, limitations, and strengths before providing a conclusion. The experiences that participants shared provided rich information. Based on this information, I offer implications for healthcare practitioners (HCP) to improve not only their awareness and education surrounding endometriosis, but also their ability to empathise with patients. Following this, I make suggestions for how coaches, support staff, and others providing social support can help to recognise endometriosis and provide an environment that reduces stigma to encourage athletes to speak up. Following this, I suggest strengths and limitations of this study before providing concluding remarks.

### **Implications**

Participants described their endometriosis-related pain as a rain cloud that burdened every part of their story. Part of this burden was the significant amount of time and resources spent in order to get the correct diagnosis and subsequently, treatment. Participants were often misdiagnosed with conditions including nerve irritation, back pain, pelvic inflammatory disease, and even sexually transmitted infections (STI) and endured ineffective treatments due to these misdiagnoses. Accordingly, participants stressed the importance of HCP being educated about endometriosis in order to avoid these lengthy wait times and misdiagnoses. HCP should aim to be informed with up-to-date information about endometriosis and equipped to quickly recognise this highly prevalent disease; further, they should be ready to take swift action in treatment (see also Culley et al., 2013; Moradi et al., 2014; Young et al., 2015).

Additionally, HCP who work with athletes should expand their understanding to be aware of the possible effects of endometriosis on sport—and how this can impact patient decision-making, as well as needed accommodations. As participants identified that their pain

impacted their sleep, fatigue levels, and in turn performance, pain-related sleep and fatigue issues need to be addressed to maintain optimal performance (see also Watson, 2017). Athletes need to take time off training to be able to have surgery and therefore, where possible it needs to be scheduled at an appropriate time in the season where there is a significant period of rest possible. It is important that HCP are aware that delaying treatment may be the only option, as athletes' career progress or season commitments may depend on the timing. Additionally, as guidelines for returning to sport post-surgery are yet to exist, HCP should also seek to contribute to developing a general guide for returning to sport taking into account the demands of each sport.

In addition to a lack of education about endometriosis amongst HCP, participants identified that a culture of minimising and invalidating contributed to their suffering. These experiences led to participants feeling 'dismissed', 'not listened to' and wondering if they were 'going crazy'. This created a sense of conflict between the participants' embodied experiences, and the expertise of the HCP (see also Kool et al., 2013). Contributing to this was 'masculinised knowledge' and historical discourses of hysteria which left little room for understanding embodied female experiences (see also Davis-Floyd & Sargent, 1997; Young et al., 2019). This suggests a greater need for HCP to be more attuned to how athletes are communicating about their embodied experiences and that HCP need to be equipped with the knowledge of female embodied experiences and provide an empathetic stance when listening to patient stories. This requires HCP to acknowledge women's knowledge of their own bodies and consider the patient's experience more significantly. Further, a key part of this is understanding that athletes typically avoid being seen as weak (Wilson et al., 2021), so when they do speak up about their pain, it is vital to take them seriously. Achieving this will likely require an approach where HCP

improve attitudes about endometriosis and where women's experiences are assessed and addressed according to their concerns (see also Young et al., 2019).

In terms of mental health, participants experienced a 'mental toll' where they were psychologically impacted by these experiences. Participants described experiencing profound and intense symptoms including depressed mood, diminished pleasure in normal activities, fatigue, loss of energy, feelings of worthlessness and even recurrent thoughts of death. Considering that athletes are at a higher risk of suicide (Peterson et al., 2018; Timpka et al., 2021), and half of women with endometriosis have suicidal thoughts (BBC, 2019) it is particularly important that HCP also screen for mental health concerns and refer appropriately for additional support when appropriate.

As with HCP, participants felt as though their coaches (who were mostly male) and support staff had a low understanding of endometriosis. This meant that participants endured a culture of being minimised and invalidated. This was likely compounded by power relations between the male coach and female athlete which can create a sense of vulnerability in sporting environments (see also de Haan & Norman, 2020). It was often up to the athlete to educate their coach on endometriosis and whether participants were able to do so appeared to depend on the confidence and assertiveness of the athlete, as opposed to the communication style of the coach.

Considering the prevalence of endometriosis is around 8% in athletes (Heather et al., 2020) or possibly higher (Pettersson & Berterö, 2020), coaches and support staff should seek to understand how it presents, and where to refer their athletes for screening and treatment for endometriosis. This requires staff to confront taboos that exist around women's bodily functions (Price & Shildrick, 1999; Shildrick & Price, 2017), and actively reduce stigma by facilitating conversations about menstrual health, and the impacts of periods on life and performance.

Following surgery, participants often became more ‘in tune’ with their bodies, and some began to plan their training around their menstrual cycle. This took the pressure off trying to perform on days with significant pain and heavy bleeding and these participants noticed performance improvements by adopting this training style. Other research in this area is growing and displays promise (Carmichael et al., 2021; Clarke et al., 2021). Coaches could potentially grow their knowledge of this area and consider individualising training around the menstrual cycle. Additionally, when athletes present with pain, coaches and support staff can encourage athletes to track their pain symptoms along with their period to observe related patterns.

Additionally, participants found the return to training and competition difficult due to mixed messaging and the previously noted lack of guidelines that were specific to athletes from HCP. Coaches and support staff should work together with HCP to ensure that the athlete is well supported in their return to training and competition. Support staff could also assist in recognising and appropriately referring for mental health concerns and make efforts to reduce the stigma of mental health by facilitating healthy conversations. Lastly, while participants identified that their partners, families, and friends were mostly protective, for some, their social support network could be enhanced by additionally increasing their awareness of endometriosis. Improved attitudes, education and further research among HCP, coaches and support staff and social supports could improve the life situation of athletes with endometriosis (see also Pettersson & Berterö, 2020).

### **Strengths and Limitations**

Women were recruited for this study online via social media, a method of recruitment which has several limitations. Firstly, some of the participants knew me through sport, which may have encouraged them to participate where they otherwise would not have. While I made

efforts to explain that participation was voluntary through the informed consent process, some may have felt compelled to participate to be supportive.

Secondly, the study may have attracted those who felt as though they needed more support or who were experiencing more severe symptoms. Thirdly, the recruitment method may have contributed to the low diversity in participant characteristics. Participants were from New Zealand, Australia and the UK and competed in athletics, gymnastics, rowing, martial arts and cycling (including track, road, and mountain bike). This research should not be considered representative across diverse groups such as para-sports nor across different sports. The unique challenges that some athletes may face were not addressed in this study.

Another limitation within this study was the considerable amount of rich qualitative data uncovered from the participant accounts. The limitation here was the inevitable inability to completely represent every nuance within such rich qualitative data. Finding ways to present the amount of information was challenging as I viewed every aspect of participants' stories as important. However, due to the scope of this study, only four key themes were focused on.

A strength of this study was the personal experiences that I had in both sport and having endometriosis. I believe this offered me insight into participant experiences and helped me to understand their stories while offering solidarity and appreciating their experiences. While also noted as a limitation, knowing some of the participants was also a strength as it meant rapport was already established and participants likely felt comfortable sharing information. In addition, the richness of the qualitative data strengthened this study. The participants were brave in openly explaining and elaborating on, what were extremely challenging experiences which added depth and richness to the findings. The final strength of this study that I will acknowledge was that this

research is among the first to address this topic of assessing how endometriosis affects the lives and wellbeing of athletes.

## **Conclusion**

In concluding this thesis, I reflect on previous research before reviewing the aims of the study, reiterating the findings of this thesis, and providing a closing statement. Endometriosis is a disease characterised by CPP with a prevalence of around 8% in athletes. This study was among the first to investigate how endometriosis affects athletes. As noted in the literature review, only one study on an athlete with endometriosis was identified. Other research on endometriosis in general revealed the physical and psychological burden that women endure. This was illustrated in the current study, but with additional specific effects on sport.

This research aimed to evaluate the impact of endometriosis on the lives and well-being of female athletes. This was completed by using semi-structured interviews to gather participant information. These were then recorded and transcribed before being analysed using reflexive thematic analysis. Following this, four themes were developed:

Theme One: “A Cloud Over You” The Burden of Endometriosis

Theme Two: “How was your Holiday?” Experiences of Invalidation and Minimisation

Theme Three: Recognising “Maybe This Isn’t Normal” Advocacy and Overcoming

Theme Four: “Thank God I’ve Got an Answer” Misdiagnoses, Diagnoses and Treatments

These four themes were based on three aims which are identified next.

The first aim was to understand the symptoms, journey to diagnosis, and treatment experiences of female athletes with endometriosis. In investigating this I found that participants experienced significant burden with enduring painful symptoms and arduously long journeys to diagnosis and treatment. This included poor accessibility to appointments and many



misdiagnoses. This took a toll on both their physical and mental health and produced significant distress. Participants felt as though they had to advocate for themselves in order to receive adequate care or rely on someone else to do so until finding someone who made a difference. Participants explained that somewhere on their journey, they connected with ‘that one person’ who took their pain seriously and changed the course of their journey. After having surgery and receiving a diagnosis, participants felt validated and relieved. Yet following this, participants underestimated how long recovery would take and realised that surgery did not completely cure them, leaving them with concerns about the future of their sport and in general.

My next aim was to understand the impact of endometriosis on sporting lives, including selection, and relationships. Here I found that participants were negatively impacted in their sporting lives. Participants went to great lengths to conceal their pain due to fears of being seen as weak in their sport and experienced stress in their relationships with coaches and support staff due to endometriosis. Participants demonstrated how power relations between their male coach and them as a female athlete created a sense of vulnerability which made them unwillingly complicit with dominant discourses from coaches because their funding and selection were at stake. Additionally, after surgery, participants received mixed messages regarding advice on returning to sport and noted the lack of guidelines specific to athletes. Finally, participants shared how their approach to training had changed following their diagnosis and how they became better at ‘listening to their body’. However, participants often had their identity intertwined with their sport and found that when sport was not going well due to endometriosis, their mental health took a toll.

This mental toll was additionally relevant to the third aim of this project which was to evaluate the effects of endometriosis on female athletes’ wellbeing, mental health, and future

aspirations. In terms of wellbeing, participants described how they were often invalidated and minimised by those around them. This put strain on their relationships with friends and family and with HCP. This additionally impacted their wellbeing and mental health by making them feel ‘depressed’, ‘not listened to’ or as though they were ‘going crazy’. In terms of future aspirations, some were worried how endometriosis might affect them in the future and shared concerns about their future pay, selectability or even considered retirement due to endometriosis.

Implications of these findings include the need for HCP to improve their awareness of endometriosis and its impact on sport. This also requires HCP to become equipped with knowledge of female embodied experiences and to be empathetic and pay attention when athletes speak up. It is additionally paramount for HCP to screen for mental health concerns. Implications for coaches and support staff also include increasing their awareness, but additionally to facilitate open conversations about women’s health in general to reduce stigma. Coaches and support staff can also seek to plan training around the menstrual cycle for performance benefits. Lastly, HCP and sport staff should work together to develop guidelines around training with endometriosis, surgery, and the subsequent return to sport.

Overall, this study reinforced current knowledge about women with endometriosis and the associated burden. As a previously unexplored area of the literature, this project illustrated how athletes specifically are impacted in their sporting lives. Additionally, this research provided recommendations for people involved with athletes and a demonstrated a rationale to explore this topic further.

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## Appendices

### Appendix A: Advertisements

#### 1. Facebook Advertisement:

Massey University

# Athletes with Endometriosis

**Research**

If you are an athlete and:

- Have been diagnosed with endometriosis
- Are over the age of 18
- Have competed at a national or international level in your sport

You are invited to take part in this study, which involves an interview.

For more information or to take part, please contact:

Email:  
[kirstie.klingenberg.1@uni.massey.ac.nz](mailto:kirstie.klingenberg.1@uni.massey.ac.nz)

MASSEY UNIVERSITY MASTER'S THESIS

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 21/46. If you have any concerns about the conduct of this research, please contact A/Prof Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800, x 43347, email [humanethicsnorth@massey.ac.nz](mailto:humanethicsnorth@massey.ac.nz).

## 2. Instagram Advertisement

Massey University

# Athletes with Endometriosis

**Research**

Are you an athlete with endometriosis over the age of 18 willing to take part in research? Swipe across:

Email:  
kirstie.klingenberg.1@uni.massey.ac.nz

THE IMPACT OF ENDOMETRIOSIS ON FEMALE ATHLETES' LIVES AND WELLBEING:  
A QUALITATIVE STUDY  
MASSEY UNIVERSITY MASTER'S THESIS

If you are an athlete and:

- Have been diagnosed with endometriosis
- Are over the age of 18
- Have competed at a national or international level in your sport

You are invited to take part in this study, which involves an interview.

For more information or to take part, please contact:

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## Appendix B: Consent and Transcript Release Form

The Impact of Endometriosis on Female Athletes' Lives and Wellbeing: A Qualitative Study

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I have read, or have had read to me, and I understand the Information Sheet that I received by email.

I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study up until two weeks after signing the transcript release form.

I agree to the interview being sound recorded.

I agree to participate in this study under the conditions set out in the Information Sheet.

I consent

I do not consent, I do not wish to participate

---

I wish to have my recordings returned to me

Yes

No

---

Please type full name

---

Please sign:

×

SIGN HERE

clear

## Appendix C: Information Sheet



### ***The Impact of Endometriosis on Female Athletes' Lives and Wellbeing: A Qualitative Study***

#### INFORMATION SHEET

##### **Researcher**

My name is Kirstie Klingenberg, and I am a master's student at Massey University. I am also a professional track cyclist who has endometriosis and am very interested in how endometriosis affects athletes. I am an athlete who has endometriosis and I am interested in the experiences of other athletes who have endometriosis as well. I am undertaking this project for my thesis. My supervisor is Dr Andrea LaMarre, lecturer in critical health psychology at Massey University.

##### **Aim**

Research shows that endometriosis has an impact on the quality of life of women in areas like social wellbeing, health, self-esteem and productivity. Additionally, endometriosis can impact fertility, sexuality and personal relationships. In this study I aim to explore the effect of endometriosis on wellbeing and lives of athletes. I hope that this study will lead to additional research in the area and hopefully better outcomes for those affected.

Your participation in this research project is entirely voluntary. If you do agree to participate, you can withdraw from the research project without comment or penalty. You can withdraw anytime during the interview. If you withdraw within 2 weeks after your interview, on request any identifiable information already obtained from you will be destroyed.

##### **Participant Identification and Recruitment**

I am reaching out to you as I think you may be interested in taking part in my study.

To be included in this study you need to:

- Have been diagnosed with endometriosis
- Be over the age of 18
- Be an athlete who has competed in national or international competitions.

I am looking for approximately 7-10 participants will be included; this will allow me to understand stories in depth, rather than looking to make broad-sweeping generalizations.

If you decide to participate, you will be asked to take part in an online (Zoom) or in person interview, where you will be asked a set of questions regarding experience with

endometriosis. This will take approximately **60 to 90 minutes** of your time and it will be audio-recorded for analysis.

As a thanks for your time, you will receive an honorarium in the form of a \$40 NZD gift card for Countdown or local supermarket voucher if you are not in New Zealand.

**Discomforts, risks and benefits.**

Partaking in this interview may bring up negative thoughts or feelings associated with your experiences of having endometriosis. If at any time you wish to discontinue, including during the interview, you may. You can also choose to not answer particular questions that cause you distress or that you do not wish to answer. If any distress arises for you during or after the interview, we have provided a list of resources below that we invite you to reach out to:

There are no direct benefits to participating, but the results of the study may help to deepen understandings of athletes' experiences of endometriosis and hopefully encourage further research in the area.

[the following section will be tailored to the region of the participant]

Distress lines:

LIFELINE : 0800 543 354  
NEED TO TALK? Call or text 1737  
SAMARITANS : 0800 726 666  
DEPRESSION HELPLINE : 0800 111 757  
[mentalhealth.org.nz](http://mentalhealth.org.nz)

**Data Management**

The interview recording will be transcribed by the researcher. The transcriptions will be analysed using thematic analysis and key themes will be discussed in relation to the research question.

Following the analysis of the interview you will have the opportunity to view the interview transcript and respond if you feel corrections are required or if clarification is necessary.

You will have the opportunity to choose a pseudonym (fake name), which will be used to identify you instead of your real name in any write ups.

Additionally you will be given the opportunity to check any specific quotes that have been selected to be included in the final study and potentially in publications.

If you do not respond within two weeks of these emails, I will assume that you do not wish to make changes.

Finally you will receive a summary of the research results at the completion of the study.

Audio recordings and transcripts will be securely stored on a password protected computer for up to five years before being destroyed.

### **Participant's Rights**

You are under no obligation to accept this invitation.

If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study up until two weeks following signing the transcript release form
- ask any questions about the study at any time before or during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher
- be given access to a summary of the project findings when it is concluded.
- ask for the recorder to be turned off at any time during the interview.

### **Project Contacts**

Researcher: Kirstie Klingenberg

Contact: [kirstiekberg@gmail.com](mailto:kirstiekberg@gmail.com)

Supervisor: Andrea LaMarre

Contact: [A.LaMarre@massey.ac.nz](mailto:A.LaMarre@massey.ac.nz)

Please contact the researcher or supervisor if you have any questions.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application \_\_\_/\_\_\_ (*insert application number*). If you have any concerns about the conduct of this research, please contact Dr Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43347, email [humanethicsnorth@massey.ac.nz](mailto:humanethicsnorth@massey.ac.nz).



## Appendix D: Interview Guide

### **Semi- Structured Interview Guide for Master's Thesis Study: The Impact of Endometriosis on Female Athletes' Lives and Wellbeing: A Qualitative Study**

#### *Background Information: General*

Why were you drawn to the research/why were you interested in participating

How old are you?

What sport do you compete in?

How long have you been competing?

What is your proudest achievement in your sport?

Why did you choose your sport?

How long do you plan to continue in your sport?

#### *Background info: endometriosis*

What have your main symptoms been?

- If pain, is it debilitating? eg. Can't train or compete

Can you tell me about your journey to diagnosis?

- What were some of your symptoms?
- When did you decide to reach out for medical help? What was the path to diagnosis like?
- Did you encounter any barriers to treatment?
- How did you feel when you were diagnosed?

What treatments, interventions or medications have you tried?

- What kind of surgery have you had?
- Was it helpful?
- Did you experience relief?

Were you satisfied with your treatment?

- Was there another treatment you wanted to get that you didn't have access to?

## *Sport*

Has endometriosis affected your life as an athlete?

- If so, how so?

Prompts:

- Selectability
- Pay
- Relationships with other athletes
- Relationships with staff
- Willingness to continue competing.
- What effects do your symptoms have on your sport?

Has endometriosis affected your wellbeing as an athlete?

- If so, how so?

Prompts:

- Happiness
- Connection
- Sense of purpose
- Physical health
- Emotions
- Stress
- Sense of security

## *Future*

How do you think your life athlete might be affected by endometriosis in the future?

Is there anything I haven't asked you that you hoped we would talk about today or that you wanted to share?

If you were to give yourself advice as a young athlete with endometriosis, what would it be?

## Appendix E: Ethical Approval Letter



18/08/2021

Dear: Kirstie Klingenberg

**Re: Ethics Application - NOR 21/46 - The Impact of Endometriosis on Female Athletes' Lives and Wellbeing: A Qualitative Study**

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

**Human Ethics Northern Committee** at their meeting held on **Thursday, 24 June 2021**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson  
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise  
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840 E  
humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

Report Parameters: Application code

NOR 21/46