

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

Running head: ENDOMETRIOSIS & YOGA

Endometriosis & Savasana: Exploring Pain Management for Endometriosis Through the Practice of  
Yoga

A thesis presented in partial fulfilment of the requirements for the degree of

Master of Arts in  
Psychology

at Massey University, Albany, New Zealand.

Pretty Samudraningsih

2023

### Abstract

Endometriosis is an illness impacting approximately 10-15% of women globally (Goncalves et al., 2017). A debilitating disease, endometriosis can affect females of reproductive age. Common symptoms of endometriosis can include chronic pain, dysmenorrhea, painful intercourse, abnormal menstrual bleeding, and infertility (Endometriosis New Zealand, 2023). Currently, there are no definitively effective treatments for endometriosis and therefore it is imperative to explore different methods of pain management. Pain can be a burden to not only physical health, but also have adverse implications on other elements in an individual's life such as their mental health, interpersonal relationships and work, ultimately affecting self-perceived QOL. The purpose of this research was to investigate the efficacy of yoga, a non-medical practice that values the balance between the mind and body, in reducing perceived pain caused by endometriosis. Three women with confirmed diagnosis of endometriosis participated in the research. Single semi-structured interviews were conducted prior to the research starting and at the end of the research, and participants also completed a 25-question endometriosis health questionnaire at these times. A shortened 5-question version of this questionnaire was also given to the participants 6 weeks into the research. Participants answered a daily pain scale and wrote in their journals every day for 12 weeks. Participants started to attend the yoga class four weeks into the research for the next 8 weeks. Six key themes were found within the participants' datasets of their journal entries and their initial and closing interviews: (1) experiencing endometriosis pain, (2) treating endometriosis pain, (3) yoga and QOL, (4) benefits of yoga on the body, (5) benefits of yoga on mental health, and (6) yoga and perception of pain. Overall, yoga was found not to be effective for perception of pain associated with endometriosis but the participants' perceived QOL improved in certain mental and physical health domains including social support, mindfulness and body awareness, physicality (e.g. flexibility, toning) and confidence. The implications of the research suggest that QOL and pain for women with endometriosis is complex so pain management for endometriosis ideally should be grounded in the person's world and holistic (considering all domains). More research is needed on both yoga for endometriosis in Aotearoa New Zealand and on pain management for chronic health conditions.

### **Acknowledgements**

I want to thank my supervisor, Dr Kathryn McGuigan. Thank you for having faith in me and my research. You have supported me immensely throughout this year and shown me guidance in my research. You have devoted so much of your time and effort to me and my research, and for that I am very grateful. Thank you for all your feedback and ideas and for all your help. Your creativity and commitment motivated me to keep learning and keep thriving to do my best. You have challenged me and helped me grow, and I am thankful for everything that you have taught me. You have been so kind and supportive throughout this journey and I will never forget this experience.

Next, thank you to my husband-to-be, Joe. Thank you for always being there for me and supporting me. Thank you for your positivity and the endless laughs, and for your constant motivation and support in the completion of my thesis. From planning a wedding and doing my research amongst everything else going on in our lives, you have been understanding and patient, and for that I am forever grateful. Thank you to my family for always encouraging me and pushing me to achieve my goals and for supporting me in whatever I choose to do in life. I hope that I can make you all proud of me.

Thank you to Samantha for all your time and effort in conducting the yoga classes for my research. Thank you for creating a warm and welcoming space for myself and the participants, and for teaching us to be comfortable in our bodies. Thank you for sharing your knowledge and abilities in yoga with us.

Finally, thank you to the five women who devoted their time and effort in participating in my research. Thank you for giving your time so generously and for sharing some of your most personal and challenging experiences with me. You were strong in sharing your journeys with endometriosis with me, and thank you for your patience and faith in my research. Thank you for giving me this opportunity. I am incredibly grateful that you shared this experience with me.

**Table of Contents**

Abstract ..... 1

Acknowledgements ..... 2

Table of Contents ..... 3

Chapter One: Introduction ..... 7

    What is Endometriosis? ..... 7

    Symptomatology ..... 9

    Medical Aetiology ..... 9

*Genetics & Environmental Factors* ..... 11

    Diagnosis in New Zealand ..... 11

    Treatment of Endometriosis ..... 12

    Endometriosis & Quality of Life ..... 14

    Research Aims ..... 17

*Objectives* ..... 17

Chapter Two: Literature Review ..... 19

    Pain ..... 19

*Biomedical Approach* ..... 19

*Biopsychosocial Approach* ..... 22

*Enactive Approach* ..... 27

*Feminist Theory* ..... 30

    Theoretical Perspective Adopted in This Research ..... 33

    QOL in the Context of Aotearoa ..... 33

    QOL Domains in the Context of Endometriosis ..... 36

    Yoga for Pain Management ..... 37

*Mind-Body Intervention for Endometriosis Pain Management* ..... 39

*Physical Activity & Exercise for Endometriosis Pain Management* ..... 41

    Conclusion ..... 42

Chapter Three: Methodology ..... 43

    Critical Realism ..... 43

    Reflexive Thematic Analysis ..... 44

<i>Reflexivity</i> .....	45
Ethics.....	47
Procedure .....	48
<i>Recruitment and Participants</i> .....	48
<i>Participants' Initial Interviews</i> .....	51
<i>Journals and Pain Scales</i> .....	52
<i>Yoga Sessions</i> .....	52
<i>Second Interviews</i> .....	54
Challenges.....	54
Analysis.....	56
<i>Scoring of Endometriosis Questionnaires</i> .....	56
<i>Pain Graphs</i> .....	57
<i>Reflexive Thematic Analysis</i> .....	58
Chapter Four: Findings .....	61
Overview of Themes and Subthemes.....	61
Theme One: Experiencing Endometriosis Pain .....	62
<i>Pain and Diagnosis Journey</i> .....	63
<i>Control and Powerlessness</i> .....	64
<i>Intersection of Mental and Physical Wellbeing</i> .....	65
<i>Pain and Quality of Life</i> .....	66
<i>Conclusion</i> .....	67
Theme Two: Treating Endometriosis Pain .....	68
<i>Medical Options</i> .....	68
<i>Lack of Options</i> .....	69
<i>Self-Management</i> .....	70
<i>Conclusion</i> .....	71
Theme Three: Yoga and QOL .....	71
<i>Participants' Endometriosis Health Questionnaires</i> .....	72
<i>Summary of Perceived QOL</i> .....	78
<i>Mental Wellbeing</i> .....	82
<i>Self-Image</i> .....	83
<i>Social Support</i> .....	84
<i>Conclusion</i> .....	85
Theme Four: Benefits of Yoga on the Body .....	85
<i>Flexibility</i> .....	86
<i>Muscle Toning</i> .....	86
<i>Physical Capability</i> .....	87
<i>Short-Term Pain Relief</i> .....	88
<i>Conclusion</i> .....	89
Theme Five: Benefits of Yoga on Mental Health .....	89

## ENDOMETRIOSIS & YOGA

<i>Confidence</i> .....	89
<i>Control</i> .....	90
<i>Independence</i> .....	90
<i>Conclusion</i> .....	91
Theme Six: Yoga and Perception of Pain .....	91
<i>Participants' Daily Pain Scales</i> .....	92
<i>Participants' Reflections on Yoga Experience and Impacts on Endometriosis</i> .....	96
<i>Conclusion</i> .....	98
Chapter Five: Discussion .....	100
Summary .....	100
<i>QOL and the Complexities of Living with Endometriosis</i> .....	103
<i>Experience, Perception &amp; Memory of Pain</i> .....	104
Strengths & Limitations .....	106
Practical Implications .....	109
Conclusion .....	111
References .....	112
Appendices .....	127
Appendix A: Cultural Plan (Protocols) for Māori Participants .....	127
Appendix B: Advertisements .....	132
Appendix C: Information Sheets .....	135
Appendix D: PAR-Q Health Screening Questionnaire .....	141
Appendix E: Consent Form .....	142
Appendix F: Yoga Instructor Confidentiality Agreement and Behaviour Guideline .....	144
Appendix G: Interview Guide & Safety Plan for Interviews .....	146
Appendix H: Journal Formats .....	154
Appendix I: Endometriosis Health Questionnaires .....	157
Appendix J: Themes and Subthemes Found Within Participants' Datasets. ....	160

**List of Tables and Figures**

Table 1. Participants’ Demographic Characteristics .....49

Table 2. Focus of yoga sessions ..... 53

Table 3. Themes and subthemes related to the effectiveness of yoga as pain management for  
endometriosis ..... 62

Table 4. Endometriosis Questionnaire Scores Obtained at the Start of the Research (Out of 100)...72

Table 5. Endometriosis Questionnaire Scores Obtained at the Middle of the Research (Out of 100)  
..... 74

Table 6. Endometriosis Questionnaire Scores Obtained at the End of the Research (Out of 100).... 76

Table 7. Miriam’s Endometriosis Health Questionnaire Scores ..... 79

Table 8. Tessa’s Endometriosis Health Questionnaire Scores ..... 80

Table 9. Margaret’s Endometriosis Health Questionnaire Scores ..... 81

Table 10. Miriam’s Mean and Median Pain Scores ..... 92

Table 11. Tessa’s Mean and Median Pain Scores ..... 93

Table 12. Margaret’s Mean and Median Pain Scores ..... 95

Figure 1. Outline of Procedure Carried Out in Research .....48

Figure 2. Pre-test Endometriosis Health Questionnaire Scores ..... 73

Figure 3. Mid-test Endometriosis Health Questionnaire Scores ..... 74

Figure 4. Post-test Endometriosis Health Questionnaire Scores ..... 76

Figure 5. Miriam’s Endometriosis Health Questionnaire Scores ..... 79

Figure 6. Tessa’s Endometriosis Health Questionnaire Scores ..... 80

Figure 7. Margaret’s Endometriosis Health Questionnaire Scores ..... 81

Figure 8. Miriam’s Mean and Median Pain Scores ..... 92

Figure 9. Tessa’s Mean and Median Pain Scores ..... 94

Figure 10. Margaret’s Mean and Median Pain Scores ..... 95

## Chapter One: Introduction

Pain is often associated to menstruation and is considered a normal part of being a woman<sup>1</sup>. With endometriosis the pain experienced is often severe, impacting daily functioning, such as the ability to go to work or school, and quality of life. Endometriosis is a common illness primarily affecting women around the world across different backgrounds, but despite its commonality, knowledge about the condition and its treatments are unfortunately still not fully understood. In addition, there is still no definitive cure, leaving women with very few options and solutions. This highlights the importance of finding effective pain management methods. Yoga has been shown to be effective in helping people cope with pain, reducing pain levels through the various poses and stretching techniques, as well as implementing mindfulness (Doulatabad et al., 2013). The purpose of this qualitative research is to investigate endometriotic women's experiences with yoga to see if there are benefits to pain levels and quality of life.

The aim of the introduction chapter is to define endometriosis, the symptoms, diagnosis, treatments and aetiology. I will also explain the reasoning behind the implementation of yoga in this research. I will then outline my research aims.

### What is Endometriosis?

Endometriosis is a chronic inflammatory condition that affects a large population of women across the globe. Approximately 10-15% of women worldwide have endometriosis (Goncalves et al., 2017). In Aotearoa New Zealand, the percentage of women affected by endometriosis is just as high, estimating to impact 1 in 10 Kiwi women - roughly 120,000 women (Endometriosis New Zealand, 2023; Ministry of Health, 2022). It is most commonly diagnosed in women of reproductive age (25-35 years old), however, endometriosis can develop in younger years. In adolescent and teenage girls experiencing chronic pelvic pain (CPP) and dysmenorrhea, between 19-73% of those who underwent laparoscopic surgery had presented with endometriosis (Jansen et al., 2013). Furthermore, transgender and non-binary people can also be at risk for endometriosis, as it can affect anyone who is assigned female at birth, those who are born with a uterus (Endometriosis New Zealand, 2023; Insight Endometriosis, n.d.b).

Endometriosis is an oestrogen-dependent disorder that can be characterised by the presence and development of endometrial tissue, (which is usually found in the lining of the uterus), outside

---

<sup>1</sup> I will use the term 'woman' or 'women' in this thesis but acknowledge that there are people who menstruate who may not identify as a woman or female. Additionally, endometrial cells have been found in cisgender males, however, endometriosis still remains as a health issue that predominantly affects cisgender females of reproductive ages.

## ENDOMETRIOSIS & YOGA

of the uterus and in other parts of the body (Agarwal et al., 2021). The tissues can form lesions and glands, such as ovarian cysts (endometriomas). These endometrial cells can form and be found in organs in the pelvic region, such as the ovaries, fallopian tubes, bowels, rectum, bladder, and pelvic lining, called the peritoneum (Insight Endometriosis, n.d.c). In more rare cases, endometriosis can also be found outside of the pelvic region, such as in the intestines, abdominal wall and thoracic cavity (Hirata et al., 2020). During a menstrual cycle, hormones from the ovaries stimulate endometrial tissue to grow, lining the uterus and getting the body prepared for pregnancy. If pregnancy does not happen, the hormone levels decrease, causing the endometrial tissue to shed, generating a period. With endometriosis, the endometrial tissue that grow outside of the uterus still operate the same as they would inside the womb- responding to the same hormones, growing and bleeding (Health Navigator New Zealand, 2023). When this happens, there is no way for blood to exit the body and therefore becomes trapped. Inflammation occurs due to this internal bleeding, scar tissues and adhesions can also develop, creating fibrous tissue that can cause pelvic tissue and organs to bind together (Women's Health Action, n.d.). This can be very painful, hence why women who have endometriosis often feel pain during their period, pain at certain times of their cycle, and prior to or after menstruation (Health Navigator New Zealand, 2023). Left untreated, endometriosis can cause detrimental problems, such as scarring, cysts, further damage in pelvic lining and other organs, chronic pelvic pain and problems with fertility (Women's Health Action, n.d.).

Severity of endometriosis is categorised biomedically into stages one to four (Parasar et al., 2017). The system used here in New Zealand is the classification scheme by the American Society for Reproductive Medicine (ASRM). There are four stages, (stages I-IV), based upon a numerical point scale threshold, and patients are scored depending on the spread and depth of infiltration, peritoneal and pelvic implants, development of cysts and extent of adhesions (Insight Endometriosis, n.d.c; Parasar, et al., 2017). For example, stage III can also be considered as a 'moderate' stage, describing more widespread endometriosis and infiltration to the pelvic and other organs, some small cysts can be seen, with some scarring and adhesions present (Endometriosis New Zealand, 2023). On the other hand, stage IV is ranked as the 'severe' stage, where large cysts are present, adhesions are acute and spread of endometriosis has caused some distortion to anatomy (Health Navigator New Zealand, 2023). Using this classification system can be very helpful for medical professionals in assessing endometriosis and the severity of the illness. It gives them information on what characteristics of endometriosis to look for, extent of endometriosis, and provides prediction of pain and fertility (Lee et al., 2021). This staging system by the ASRM can

## ENDOMETRIOSIS & YOGA

also act as a guideline to help analyse the appropriate treatments suitable for the patients as well as the urgency and complexity of surgery they may need to perform.

It is important to note that the stages of endometriosis are not definitively correlated to the symptoms or level of pain the patient experiences (Fedele et al., 1990). In addition, due to the broad variety of symptoms, the impact that endometriosis has on each individual will be very different as it depends on the severity of endometriosis, organs affected, and the extent of scar tissue or adhesions. Unfortunately, it is these individual differences that can make it difficult for medical professionals to distinguish and diagnose endometriosis. Nevertheless, official classification systems have been developed to aid medical professionals in identifying endometriosis and determining the severity of the illness (Lee et al., 2021).

### **Symptomatology**

Some women who have endometriosis may be asymptomatic and undiagnosed and it is estimated that approximately one third of women who have endometriosis are asymptomatic (BPACNZ, 2021). However, the rest endure various and often extensive painful symptoms. This points to the complexity of understanding endometriosis and how individualised the condition can be. Endometriosis symptoms can start at younger years even during pre-reproductive age for some women. The time between onset of symptoms and diagnosis can take up to 12 years (DiVasta et al., 2018; Agarwal et al., 2021). Physiological symptoms of endometriosis often include chronic pelvic pain (CPP), dysmenorrhea, dyspareunia (painful intercourse), dyschezia (painful defaecation), dysuria (painful urination), abnormal menstrual bleeding (heavy periods or bleeding between periods), pain in other parts of body (e.g., lower back), fatigue, bloating, and infertility (Endometriosis New Zealand, 2023; Gordon et al., 2022). Pain, through dysmenorrhea is the most common symptom found with endometriosis. Due to the broad range of symptoms experienced by women who have endometriosis, some of the symptoms can be ‘camouflaged’ as normal menstrual characteristics and pain. It can also be challenging for patients and medical professionals to distinguish what differentiates normal and abnormal menstrual pain and identify what type of pain constitutes as a warning sign for endometriosis.

### **Medical Aetiology**

Discovered in the 1860s, the aetiology of endometriosis is still yet to be established. Medical professionals and researchers from various theoretical backgrounds have many different ideologies of the causes, determinants and risk factors for endometriosis. A growing body of

research supports the multifaceted idea that endometriosis results through a combination of biological, hormonal, genetic and environmental factors.

One possible explanation for endometriosis is Sampson's retrograde menstruation, and it is one theory that is widely accepted (Kuan et al., 2021). A retrograde menstruation can be described as when menstrual blood flows the wrong direction, flowing upwards through the fallopian tubes and into the pelvic space, rather than out of the vagina (Parasar et al., 2017). It is thought that through this, endometrial tissue spread and then develop in areas and organs outside of the uterus. This retrograde theory can explain ectopic lesions at different sites in the body outside of the abdominal cavity (Dinsdale et al., 2021). The problem is that most women experience retrograde menstruation to some degree (76-90% of women) (Sourial et al., 2014) yet only a smaller population develop endometriosis. Furthermore, this theory has been somewhat disputed because some areas that can develop endometriosis are not accessible to cells through retrograde menstruation (Dinsdale et al., 2021; Parasar et al., 2017), and this theory does not explain the presence of endometriosis in pre-pubescent girls, babies, and in rare cases, males (Sourial et al., 2014).

Another biomedical explanation is coelomic metaplasia theory. This theory proposes the possibility that endometriosis develops from extrauterine cells that abnormally transform into endometrial cells (Sourial et al., 2014). Within this theory is the Embryonic rest theory, hypothesising that endometriosis can develop from Müllerian duct abnormalities (Pitot et al., 2020). The Müllerian ducts are tubes that form into the female reproductive organs in foetal development, such as the uterus, cervix and fallopian tubes. It is theorised that endometriosis and endometrial lesions can form through the process of where the remnants of the developing Müllerian structure stick to the peritoneum and transform into endometrium cells (Pitot et al., 2020). Support for this hypothesis comes from the fact that Müllerian duct anomalies are seen in higher association with endometriosis, particularly when the abnormality "presents with outflow obstruction" (Pitot et al., 2020, p. 1723). Müllerian cell rests are present in women and men, this hypothesis can explain how men can present with endometriosis (Lagana et al., 2019). Because endometriosis is an oestrogen-dependent condition and oestrogen is not present in pre-pubescent girls, it is possible that this metaplasia Müllerian condition may be different from endometriosis, which is found in women of reproductive age (Sourial et al., 2014). Moreover, just like the retrograde menstruation theory, the Müllerian theory is yet to be confirmed as a definitive cause for endometriosis.

### ***Genetics & Environmental Factors***

Clinical professionals have found much support behind the heritability of endometriosis. Researchers such as Rahmioglu et al. (2015) state that family history of endometriosis can increase risk of developing the condition. The recurrence between first-degree relatives is estimated to be between 5-7% (Bischoff & Simpson, 2004). Further support for endometriosis being a hereditary condition is found through Treloar et al.'s (1999) study of prevalence of endometriosis in twins, finding that the estimated heritability amongst twins was 51%. It is proposed that because of the high prevalence of endometriosis amongst family members, polygenic inheritance of endometriosis is likely, meaning that endometriosis is likely to be regulated by more than one gene (Bischoff & Simpson, 2004). Of course, the genetic basis along with environmental factors such as upbringing, diet and lifestyle can all contribute to the onset and severity of endometriosis. There is some research surrounding the effects of diet on endometriosis (Parazzini et al., 2017) as endometriosis is associated with inflammation, menstrual cyclicality and oestrogen activity, all of which can be influenced by diet and nutrition. Researchers have investigated the association between red meat, dairy, unsaturated fats and smoking, and their roles in triggering inflammation linked to endometriosis (Goncalves et al., 2011; Parazzini et al., 2013). However, no significant data have been found to consistently support these claims and the true impact of diet and lifestyle habits on endometriosis remains ambiguous.

### **Diagnosis in New Zealand**

In New Zealand, women with pelvic pain typically seek consultation through primary health care first, going to their GP. The Ministry of Health New Zealand (2020) have a set of guidelines for medical professionals diagnosing and managing endometriosis. It is a guideline created to help medical professionals perform consistent and standardised care, diagnosis and management of endometriosis. The symptoms enlisted in the Ministry of Health New Zealand (2020) guideline are not explicit to endometriosis and the guidelines state that diagnosis of another medical condition should also be considered.

The commonly used diagnostic tools in New Zealand are ultrasound, transvaginal ultrasound, and laparoscopic surgery (Ellis et al., 2022; Berker & Seval, 2015; Insight Endometriosis, n.d.a). Ultrasound is commonly used and can be very helpful in identifying cysts and adhesions, as well as pelvic organ abnormalities. However, the results of an ultrasound alone should not determine diagnosis or non-diagnosis of endometriosis. An MRI examination is a non-invasive imaging technique that can obtain visualisation of endometriotic implants and

## ENDOMETRIOSIS & YOGA

endometriomas (Berker & Seval, 2015). Due to this imaging sensitivity, MRIs are very helpful to use in detecting deep endometriosis infiltrations in the uterosacral ligaments, bladder and pouch of Douglas (Berker & Seval, 2015). Endometriomas demonstrate a hypointense signal on T2-weighted images, which may mean that the solid lesions are benign (Park, 2014). Distinguishing this through an MRI can support for further medical examinations to be done, and GPs can refer the patient to see a gynaecologist for a more specialised diagnosis.

Diagnostic delay for endometriosis is a problem globally, including New Zealand (Tewhaiti-Smith et al., 2022). This can be because the symptoms are subjective to each individual, symptoms can be characterised as those normally present when menstruating, and there is a wide range of symptoms, some of which may be similar to symptoms of other conditions, (Insight Endometriosis, n.d.b). Lack of gynaecological knowledge can also be a factor in diagnostic delay, as most individuals would first seek medical consultation with their GP. As GPs do not have the specialised expertise in gynaecology, they may be reluctant in diagnosing someone with endometriosis, especially without conducting extensive medical examinations to prove this. In New Zealand, the average time it takes for a woman to receive a diagnosis is 8.7 years, from first symptom onset to diagnosis, and an average of five doctors had to be seen prior to finally receiving a diagnosis (Tewhaiti-Smith et al., 2022).

In New Zealand, there are various barriers to accessing health care, such as financial hardship, issues with the structural organisation of health care (e.g., lack of primary care providers), location, and personal barriers (e.g., language) (Tewhaiti-Smith et al., 2022). These barriers to healthcare access can prevent people from seeking advice from their GPs or other medical professionals, delaying possible diagnosis. Other common contributing factors in diagnostic delay are receiving a misdiagnosis, pain and/or symptoms are dismissed by the individual or their doctor (normalising of pelvic pain), and delay of being referred to a gynaecologist (Insight Endometriosis, n.d.a). Experiencing delay in getting a diagnosis for symptoms that someone feels and knows is not normal for their body can be frustrating and take a toll on their mental health, leaving women to feel doubt regarding their bodies and symptoms. Ellis et al. (2022) asked endometriosis patients what sort of emotions they felt once receiving diagnosis, and relief was the most common reaction because it affirmed that something was actually wrong with their body and not just in their head.

### **Treatment of Endometriosis**

Currently, there is no definitive cure or form of treatment for endometriosis. In New Zealand, the frontline treatment for endometriosis is hormonal medication (Ministry of Health,

## ENDOMETRIOSIS & YOGA

2020). These can be in the form of combined oral contraceptive pills (COCPs), progesterone-only pills (POPs), intrauterine devices (IUDs), and hormonal replacement therapy (HRT) (Ellis et al., 2022). The function of these hormonal medications is to prevent or get better control of menstruation. Patients can choose when to skip or have their period, and using the POP can stop them having a period altogether. In the Ministry of Health New Zealand (2020) guideline for endometriosis diagnosis, it suggests that hormonal medication should be the front-line treatment, unless the patient is trying to conceive. However, some side effects of hormonal medication such as weight gain, depression and nausea can make some patients unsuitable for taking this form of medication. In other cases, some women have also experienced that whilst hormonal medication did reduce the pain, this was only temporary, as it was not actually eliminating the illness itself. In patients that had used an IUD, only half found it effective and of those, 18% said that they wished they “never used one” (Ellis et al., 2022, p. 11). Thus, hormonal medication is seen to be only minimally effective for many, and consuming hormonal medication by themselves are not sufficient, as some women still require stronger painkillers such as opioids (Institute for Quality and Efficiency in Health Care, 2021). Opioids are not commonly prescribed by doctors in New Zealand due to its high dependency rate if used over a long period of time, but in a study by Soliman et al. (2018) in the US, 89% of participants who had endometriosis were using opioids for relieving their pain. Furthermore, although hormonal medication may be helpful in managing endometriosis symptoms in some women, its variability in effectiveness is too great to be considered a conclusive form of treatment for endometriosis and its symptoms.

Laparoscopic surgery is a form of treatment that removes endometriosis, endometriomas and adhesions. It is also used as a method to confirm diagnosis, however as it is very invasive, it is not advised for the sole purpose of diagnosis (Ministry of Health, 2020). This is problematic because if laparoscopy is the recommended procedure to obtain definitive diagnosis yet it is advised against to be performed purely for diagnosis, it seems that for a woman to be referred for a laparoscopy, previous examinations and scans would need to show presence of endometrial-like lesions in order to do the surgery. It is unsurprising then that there is diagnostic delay for endometriosis. Laparoscopic surgery has been shown to have positive impacts on patients’ symptoms such as pain, dyspareunia, and wellbeing (Vitale et al., 2017). Among women who underwent laparoscopic surgery who had deep infiltrating endometriosis (DIE- lesions at least 5mm deep) in the study by Parra et al. (2021), a majority reported improvements in their ability to perform daily activities (66.2%), improved work performance (72.7%), increased physical ability (70.1%) and increased in sexual activity (71.4%) (Parra et al., 2021). Nevertheless, laparoscopic treatment has not proven to

## ENDOMETRIOSIS & YOGA

be a permanent solution, as recurrence of symptoms affects approximately 40-50% of patients, and at times has worsened symptoms such as pain and infertility in some people (Ellis et al., 2022). Some women also have to endure multiple laparoscopies due to the recurrence of endometriosis.

When laparoscopies and other forms of treatment do not work, a hysterectomy is often recommended as a 'last-resort'. Hysterectomies can be a partial or total removal of the uterus, and a modified radical hysterectomy includes the removal of the cervix, parametrium, and areas of the vagina (Nezhat et al., 2020). An oophorectomy is when one or both ovaries are removed, and an oophorectomy can also be done during a hysterectomy. It is sometimes the case that when women experience recurrence of pain or endometriosis symptoms after repetitive treatments and surgeries, and are not concerned with preserving fertility, they may be suggested by doctors to undergo a more 'definitive' surgical treatment such as a hysterectomy or oophorectomy (Uccella et al., 2016). Unfortunately however, studies have found that while the rate of reoperation was low after a hysterectomy (Long et al., 2023), the procedure can present with adverse risks and recurrence of pain and symptoms can still occur (Uccella et al., 2016; Rizk et al., 2014). Out of 138 women in who underwent hysterectomy with preservation of ovaries, 62% of these women experienced symptomatic recurrence (Rizk et al., 2014). Other risks include organ and urinary lesions, pelvic abscess and postoperative fever. These are more likely to occur in hysterectomies performed on endometriosis patients due to the complicated nature of the disease presented through its inflammatory characteristics and adhesions (Uccella et al., 2016).

This brief discussion of the inconclusive treatments for endometriosis highlights the need for more research in this field exploring more effective treatment methods. Whilst definitive treatments are still under investigation, more attention should also be held towards finding appropriate pain management methods. Some women still experience recurring symptoms after surgery (Nirgianakis et al., 2020), but if they were able to apply pain management methods that could help them reduce the symptoms they are feeling, such as pain, this would cause a positive change in different aspects of their lives and everyday living, and improve their quality of life even more.

### **Endometriosis & Quality of Life**

Endometriosis affects many different, if not all, aspects in a woman's life. Quality of life (QOL) is a concept in which many different facets of an individual's (or society) life, including positive and negative aspects, are analysed and evaluated to establish their wellbeing (Teoli & Bhardwaj, 2022). Common facets of QOL include personal health (physical, mental, spiritual),

relationships and social belonging, work, autonomy and financial status or socio-economic status (Teoli & Bhardwaj, 2022). The WHO (2023b) defines QOL as the subjective perception an individual has on their life, and how their goals, expectations, doubts and concerns are shaped and reflected in regards to their cultural and value systems in which they live. Individuals all have different lived experiences of their lives- they have varying degrees of satisfaction and dismay, different goals and aspirations, and what elements they consider and how they measure these elements to signify QOL (Bień et al., 2020). Incorporating QOL when assessing medical care for a patient can be very beneficial, as it does not solely focus on treatment of the illness, but analyses and takes into consideration the symptoms experienced by the patient and the impacts of these on their lives and different aspects in their lives (Bień et al., 2020). This can provide for a more patient-centred approach to medical care of the patient and increase effectiveness, especially in helping with managing symptoms.

When women have endometriosis, their QOL may be adversely affected by the physical symptoms they feel such as pain, fatigue and infertility. These symptoms can also afflict their mental health and wellbeing, such as through feeling a sense of powerlessness, developing depression and experiencing decline in self-confidence (Gonzalez-Echevarria et al., 2019). The painful symptoms of endometriosis can produce a great deal of stress on the individual, as psychological and emotional distress due to experiencing such symptoms can affect the individual's perception of pain, which is associated with higher rates of anxiety and depression (Gonzalez-Echevarria et al., 2019). Furthermore, the diagnostic process itself, and how it is often prolonged for several years for the majority of women who have endometriosis, can cause a lot of burden and again, negatively impact their mental thought processes and wellbeing (Ellis et al., 2022). Feeling that there is something not right with the body you are in, yet doctors are telling you it is just menstrual pains, or are reluctant to refer you to specialists or conduct examinations, can be frustrating and make women question themselves.

Outside of their personal health, other domains in the individual's life such as work, autonomy and sexual relationships may be affected as well (Gonzalez-Echevarria et al., 2019; Martins et al., 2022). Some individuals experience immense pain, and this may prevent them from going to work/school, prevent them from being able to carry out their normal daily activities, and inhibit them from going out to social events. Pain caused by endometriosis can also affect an individual's intimacy with others and their sexual relationship with partners (WHO, 2023a). These examples of some common domains along with many others, can be affected by painful endometriosis symptoms, and as these domains are negatively impacted, an individual's perception

## ENDOMETRIOSIS & YOGA

of their QOL also decreases. The domains will be explored further in the literature review. Furthermore, pain is repeatedly seen to be the primary symptom that impacts all domains in an endometriosis patient's life (Bień et al., 2020). Therefore, it is important to acknowledge the extent that endometriosis affects a person and understand that it goes beyond just physiological implications.

### **Implementation of Yoga**

Yoga can be categorized as a practice that aims to establish a strong relationship between mind and body for health through mind-body intervention, as well as physical activity (McCall, 2013). The aims of yoga are to promote unity and harmony between body and spirit, by creating a balanced relationship between the two so that overall health and wellbeing is improved through the regularity of the mental, nervous, and immune systems (Doulatabad et al., 2013). Viewing the person as beyond their physiology signifies the appropriateness of implementing yoga in this research because by also prioritising the non-physiological aspects of a person, it shows that yoga holds a belief comparable to that of the QOL construct, in that wellbeing is made up of multifaceted physiological and non-physiological factors.

Empirical evidence has surfaced regarding the benefits of yoga on psychological and physical health. Research has found yoga to be beneficial for hormone regulation in the endocrine system by decreasing salivary levels of cortisol (stress hormone), which decreases stress and anxiety levels (McCall, 2013). Through the combination of physical exercises, relaxation and breathing techniques, yoga has suggested improvements in pain management and stress responses through the regulation of the hypothalamic-pituitary-adrenal (HPA) axis, activating the autonomic nervous system (ANS), and improving the immune system (Goncalves et al., 2017; McCall, 2013). Yoga techniques also help relax muscles, reducing pain (Doulatabad et al., 2013). These outcomes have been seen in other chronic diseases such as chronic lower back pain and multiple sclerosis (Goncalves et al., 2017). Research surrounding efficacy of yoga on endometriosis pain is still very sparse, however, the support for yoga as being beneficial in the pain management for these chronic pain conditions gives indication that yoga will hold some beneficence for the pain management of endometriosis pain too.

Yoga comprises a combination of postures (asanas), breathing techniques, meditative techniques, chants (mantras) and wisdom teachings (McCall, 2013). Yoga encourages the union of mind and body through the practice of mindfulness, which can be described as having an awareness and focus on the present moment with acceptance and acknowledgement and without judgement

(Kukihara et al., 2020). Through the practice of mindfulness, yoga has shown positive benefits of mental wellbeing, such as improving emotional regulation and resilience (Kukihara et al., 2020). Focusing on mindfulness shows that yoga understands the importance of mental wellbeing, a domain in the concept of QOL, which again shows the appropriateness of implementing yoga in this research. Yoga has also shown to improve mental health through decreasing stress levels by increasing feelings of satisfaction, self-confidence, and autonomy (McCall, 2013). While there is data to show the physical and psychological benefits of yoga, there is still very limited research surrounding the topic of yoga and endometriosis, specifically, the effectiveness of yoga in managing pain caused by endometriosis. This research aims to explore this topic and contribute to the limited current knowledge on the matter.

### **Research Aims**

In this research, it is understood that because there is currently no definitive cure to endometriosis, the focus should be directed towards finding effective pain management methods. This research will explore yoga as a form of pain management for endometriosis, as it is hoped that yoga should help with reducing painful endometriosis symptoms and participants' QOL may also improve.

The research aims of this project is to explore yoga as a method of pain management for endometriosis and its symptoms. The purpose for this research is to explore and assess the effectiveness, (if any and to what extent), of yoga in helping alleviate pain caused by endometriosis. This will be done by offering women with endometriosis the chance to try yoga for 8 weeks (more details of the methodology can be located in chapter three). A mixture of more quantitative measures of pain will be taken pre, during and post yoga sessions. In addition, the women will be interviewed about their experience of endometriosis, their pain, and their time during the yoga sessions.

### ***Objectives***

There are two main objectives. Firstly, to understand the implications of experiencing pain caused by endometriosis.

1. How do women measure and experience pain?
2. What does a woman do to reduce pain?
3. What implications does pain have on the daily functioning of her life?
4. How does the pain affect a woman's view of themselves and their QOL?

## ENDOMETRIOSIS & YOGA

5. Does a decrease in perceived pain improve an individual's QOL (based on self-reflection and test scores)?

Secondly, to explore and understand the effectiveness of yoga in reducing perceived pain caused by endometriosis and QOL.

6. What have lived experiences of the participants in this research shown in regards to the effectiveness of yoga in reducing perceived pain?
7. How do women recognise or understand that their perceived pain has changed/not changed through yoga?
8. Are there specific poses, techniques or mantras that have been useful or not useful in reducing pain?
9. Are there any other benefits from attending yoga (mindfulness, connection with other women who have endometriosis, etc.)?

### **Chapter Two: Literature Review**

This chapter will begin with an outline of what ‘pain’ is and how different theoretical approaches define pain. Within this discussion, I will also deliberate on endometriosis pain and the viewpoints of the common theoretical perspectives. The concept of quality of life (QOL) will be discussed, touching on the ‘te whare tapa whā’ framework as a notion of QOL that is implemented in Aotearoa. A depiction of the domains commonly associated with endometriosis QOL will also be illustrated, reflecting on how these will be the same domains applied in this research. A brief summary of the background and principles of yoga will be given, discussing past research on its efficacy as a form of pain management on endometriosis and other chronic pain conditions. Mind-body interventions and physical activity for endometriosis pain management will also be conferred, deliberating further supportive claims as to why yoga, a practice that combines both physical activity and mindfulness, can be an effective pain intervention for endometriosis, stating justification for its implementation in this research.

#### **Pain**

As this research will focus on pain caused by endometriosis and its symptoms, it is imperative then to first understand what is defined as ‘pain’. The International Association for the Study of Pain (Timotin et al., 2023) describes pain as, “an unpleasant subjective feeling and emotional experience associated with actual or potential tissue damage” (p. 24). Pain is often identified or felt when someone feels that something hurts, both physical and emotional. It can be unpleasant and come in different forms such as an ache, tingle, sting or burn (National Institute of Neurological Disorders and Stroke, 2023). It can come and go, happen in bursts, occur at only one point in time, or it can also be constant, such as chronic pain which persists over time. When someone feels pain, it is a signal from the brain that there is something wrong with our body, warning us of a potential or actual tissue damage (British Pain Society, 2023). Feeling this uncomfortable sensation, pain is one of the most common reasons why people seek medical consultation, and at least 20% of the global population are afflicted by chronic pain (Lena et al., 2022). How pain is viewed however, varies across different theoretical perspectives, each constituting their own definition and understandings of the concept.

#### ***Biomedical Approach***

From a biomedical perspective, the nociceptive system is responsible for the painful sensations an individual experiences (Sutherland, 2022). Humans have receptors at the end of sensory neurons all over their body which collect and are exposed to stimuli such as temperature,

pressure and vibrations (Sutherland, 2022). Each person has different tolerance levels to stimuli and when these sensory stimuli are of a certain immensity, they activate nociceptors. Nociceptors are pain receptors present throughout the body and when these are activated, signals are sent to the brain where the sensation of pain is created (Sutherland, 2022). Within this physiological theory, pain is seen as an epiphenomenon, in which it is a concept that occurs due to the tissue damage or stress (Smrdu, 2022). While the biomedical approach can be advantageous through its simplicity and straightforward nature, this model has been criticised for being reductionist. Opposing theorists suggest that the biomedical approach is limiting pain only to the physiological aspect, considering it to be a notion caused by a signalling of the brain as a consequence for tissue damage, and no non-physiological factors are considered (Bendelow, 2013). The biomedical theory ignores the possibility that non-physiological factors may have some influence in an individual's experience and perception of pain.

**Biomedical Approach & Endometriosis Pain.** According to the biomedical theory, endometriosis-associated pain should be looked at through pathophysiology, suggesting that pain has many underlying mechanisms, such as inflammation, neuropathy (damage to PNS) and nociception, and that it is very likely that endometriosis stimulates a combination of these three types of pain (Morotti et al., 2017). Albeit, not every person that has endometriosis experiences pain and the biomedical theory believes that the wide variability on pain experience is influenced by the physiological characteristics of endometriosis, such as those that are categorised in the ASRM classification system (Triolo et al., 2013). The most accepted theory of the pathogenesis of endometriosis is the retrograde menstruation theory developed by Sampson (Kuan et al., 2021). The inflammatory mechanism to endometriosis pain can fall under the category of nociceptive pain and can be associated to the retrograde menstruation theory.

In addition to the inflammatory mechanism to endometriosis-associated pain, the chronic pain often experienced by endometriosis patients can also be attributed to nociception and neuropathy through neuroangiogenesis (Maddern et al., 2020). Neuroangiogenesis is a process which occurs through the interaction of a newly-developed blood supply from pre-existing blood vessels, along with the synchronised reaction of nerve fibres (Maddern et al., 2020). Through the process of neuroangiogenesis, the new sensory fibres formed in endometrial lesions heighten the “inflammatory environment” or damage of nerves by such lesions as well as altering the peritoneal fluid, increasing the signals and activation of nociceptive neurons in the PNS which are relayed to the CNS, thus generating and sensitising the feeling of pain (Morotti et al., 2014, p. 723; Morotti et al., 2017). This dysfunction and damage of pathways in the PNS creates a disruption in the relaying

of sensory information to the CNS and a decrease of sympathetic nerve fibres that are close to the endometrial lesions (Arnold et al., 2013).

Evaluating endometriosis-associated pain and how it came to be from the biomedical view of nociception and neuropathy provides a better understanding of the extent and severity that endometriosis, and endometrial tissue, lesions and adhesions can cause on women's bodies. Nevertheless, focusing on the physiological aspects of a condition like endometriosis can be criticised as holding a reductionist view on the illness by not considering the other possible factors contributing to the individual's experience of endometriosis-associated pain (Bendelow, 2013). It ignores the implications that endometriosis can have on other aspects of the individual's life besides their physical body, and also ignores the possibility that non-physiological factors in the individual's life can affect how they experience endometriosis-associated pain, ultimately also affecting the types of treatments provided to patients. Additionally, the severity of endometriosis characteristics do not always correlate with the painful symptoms experienced by the patient (Situmorang et al., 2019), so pure reliance on the physiological mechanisms of endometriosis-associated pain should be cautioned.

**Treatment of Pain.** Treatments in the biomedical realm centre around reducing pain, taking away pain and making pain bearable. Thus with endometriosis the biomedical approach advocates for medical and surgical pain management methods (Triolo et al., 2013). Hormonal medication such as oral contraceptives are often the first point of treatment for endometriotic patients based on the belief that endometriosis and endometriosis-related pain has somatic origins (Ellis et al., 2022). Oral contraceptives are used to reduce inflammation, inhibit implantation and growth of endometriotic cells and regulate oestrogen levels all of which are actions targeted to alter the endometriotic woman's physiology (Hudson et al., 2022; Triolo et al., 2013). Surgical treatments such as a laparoscopy and hysterectomy are also methods which follow the ideology of the biomedical perspective, performed to remove endometriotic lesions with the aim to reduce and eliminate pain and other endometriosis symptoms (Triolo et al., 2013). However, hormonal medication is only partly effective in reducing pain in some women and has not been proven to actually eliminate endometriosis itself (Triolo et al., 2013). Surgery is also not a definitive form of pain management nor treatment, as recurrence of pain is often experienced by 40-50% of women who underwent a laparoscopy, with some still having to endure multiple surgeries following their first laparoscopy (Ellis et al., 2022; Nirgianakis et al., 2020).

In the current literature, there are arguments which support and go against these biomedical approaches to endometriosis treatment. As these methods have not shown to be definitive forms of

pain management or treatment, and as pain and endometriosis experience is subjective, it can be debated that perhaps interventions which also consider factors besides just biology should be taken into account, as well as implementing more individually-tailored forms of pain management.

### ***Biopsychosocial Approach***

In contrast to the biomedical model, pain can be viewed through a biopsychosocial lens. This model views the person as a whole, recognising that the mind and body are intertwined, and also acknowledges the interconnected roles that biological, psychological and social components have in an individual's perception of pain (Bervers et al., 2016). In the definition of pain by the International Association for the Study of Pain (2021), it acknowledges that pain is not just physiological, but that it is an emotional experience (Timotin et al., 2023). Actual tissue damage is not required for an individual to feel pain, and the only requirement for an individual to express that they are in pain is for them to have an experience (Craig & MacKenzie, 2021). This ideology is supported through past research that have found that there is not always an association between the pain level and tissue damage. Researchers have found that even when severe pain is felt, sometimes there may only be minimal damage detected, and vice versa, in cases where little pain is experienced, sometimes serious damage can be observed (Eccleston, 2011).

As a subjective experience, pain is not only physiological but it is also influenced by and constitutes a dynamic interweaving of emotional, social, physiological, and psychological factors. Each person acknowledges and experiences pain differently, has different tolerance levels for pain, and holds individualistic perceptions of pain. In this biopsychosocial view, personal experience and individual perception is accepted (Craig & MacKenzie, 2021). Pain is considered to still be a concept that is a consequence of sensory neuron activity in the biopsychosocial model. However, this view also understands that psychological and social components come into play and that an individual's subjective experience and perception of pain is influenced by these various components (Smrdu, 2022). The perception of pain is shaped by various elements within an individual's life, and concurrently, pain can also impact the many different domains in an individual's life, affecting their view on themselves, the world, and their evaluation of their quality of life.

Nevertheless, theorists have argued that when in application, the holistic prospect of the biopsychosocial model gets lost through the fragmentation of pain across separate elements, rather than as an entirety composed of many elements. In a clinical setting, when applying the biopsychosocial model, the patient's pain is often categorised into two (biological and psychosocial) or three (biological, psychological, social) domains (Stilwell & Harman, 2019). In

such settings however, when the domains are separated the focus tends to end up being on the biological aspect, rather than total integration of all of the domains as the model preaches. To fragment an individual's pain into components is to consider humans as straightforward and detachable, argued by critics as taking a reductionist view on the complexities of humans (Stilwell & Harman, 2019). The biopsychosocial model views a person as made up of biological, psychological and social elements so isolating these elements and arguing they are independent of one another when relating to pain is contradictory to the model's own outlook.

**Biopsychosocial Approach & Endometriosis Pain.** When discussing the impacts of endometriosis pain, the biopsychosocial model often makes references and analyses to patients' QOL which include their social, physical, psychological and cultural domains. The theory proposes that endometriosis and endometriosis-associated pain affect QOL by influencing daily functioning, intervening in social relationships and affecting mental health (Kashi et al., 2018). Looking at how endometriosis negatively impacts or causes disruptions in these domains can provide insight as to how they then have implications on an individual's perception of endometriosis pain.

**Biological Factors.** Like the biomedical approach in this aspect, the biopsychosocial model acknowledges that a woman's physiology is affected by endometriosis and that activation of sensory neurons in endometriosis can influence the individual's perception of pain (Smrdu, 2022). Endometriosis creates physiological symptoms which can cause pain, such as CPP, dysmenorrhea, dyspareunia, dyschezia, dysuria, and abnormal menstrual bleeding (Endometriosis New Zealand, 2023; Kotowska et al., 2021). The biopsychosocial model argues that the pain felt by endometriosis patients is due to a combination of changes in the nociceptive system such as activation and pathways, and the individual's own physiology and genetic makeup, ultimately influencing the individual's reaction, threshold and severity of the pain they feel (Chimenti et al., 2023; European Pain Federation, 2022). The biopsychosocial model understands that while women with endometriosis can experience pain due to the physiological changes occurring inside their bodies, it also understands that the individual is a complex being, in that their entity, perception and experience is not only influenced by biology, but through an interweaving of their biology, psychological functioning and social mechanisms.

**Psychological Factors.** The psychological factors that the biopsychosocial theory refer to in the topic of endometriosis-induced pain are those that are associated with mental wellbeing, thoughts and emotions (Smrdu, 2022). These are factors such as depression, anxiety, stress, pain catastrophising, pain coping, and self-efficacy for pain (Márki et al., 2017; Miaskowski et al., 2020). Recent studies have found a positive relationship between the level of anxiety and intensity

of pain, while a decrease in depressive symptoms was seen when intensity of pain also decreased (Márki et al., 2017). Moreover, the biopsychosocial approach recognises that psychological mechanisms can influence the individual's feeling of sensory pain and simultaneously, the physical pain can influence the individual's psychology and their perception of pain. For example, the sensory experience of pain that a woman with endometriosis feels can heighten her feelings of anxiety and worry, and increase her awareness of the sensory feeling. Also, those regularly experiencing pain may already be anticipating the feeling beforehand and thus psychologically heightens the pain when it is felt. This concept of pain catastrophising in endometriotic women has been found in previous studies, such as that by Kalfas et al. (2021). Kalfas et al. (2021) found that psychosocial factors can be affiliated with the individual experiencing a greater level of pain and that with endometriosis, depression, anxiety, and catastrophising have been linked to higher intensity of pain. Catastrophising pain symptoms can increase physiological activation of endometriosis which can then lead to increased levels of pain (Márki et al., 2017). The biopsychosocial model proposes that it is the various psychological factors and experience of pain, rather than the physiology of endometriosis itself, which can worsen symptoms and influence pain intensity and tolerability. Infertility is also an issue that endometriosis patients encounter and the strong concern about infertility may lead to persistent worry, depression and more distress (Van Stein et al., 2023).

These are all examples of psychological factors which the biopsychosocial approach considers to be effects of the physiological symptoms of endometriosis, as well as influencing factors that can alter one's "perception of a sensory stimulus that may trigger pain" (Smrdu, 2022, p. 138). From this perspective, distress and physiological pain symptoms impact each other and create a vicious cycle for women who have endometriosis (Márki et al., 2017). However, while the biopsychosocial approach proposes that psychological and physiological factors influence each other to determine perception of endometriosis pain, this theory places significant accountability on the individual for their endometriosis-associated pain by suggesting that intensity of pain is a result of the individual's inability to control their catastrophising behaviour and regulation of emotions (Kalfas et al., 2021). Placing this responsibility on the individual suggests that it is up to the women themselves to control their psychological processing and emotion regulation to manage their pain, and that failure to do so results in higher levels of pain. Affiliating the pain experienced by women with endometriosis to their psychological and emotional regulation abilities not only implies a sense of inadequacy, but also can have detrimental effects on their self-esteem and create feelings of shame.

***Social Factors.*** Enduring the painful symptoms of endometriosis can cause disruptions in the individual's social life, such as interfering with their hobbies, day-to-day activities and work, with previous studies reporting that women miss an average of seven hours per week of work due to their symptoms (Van Stein et al., 2023). Women with endometriosis may also go through social isolation or withdrawal from their relationships due to feeling judged or misunderstood by those around them such as friends and family, causing them to have an increased feeling of loneliness which can have negative implications on their psychological wellbeing as well (Van Stein et al., 2023). Previous studies have also found that between 19-48% of women who have endometriosis felt that the condition negatively impacted their social life (Culley et al., 2013b). Symptoms such as pain, fatigue and irregular bleeding not only made them worry about going out of the house, but the worry about being preoccupied of the onset of pain whilst they were out would make them depressed and angry, making them feel less able to socialise and prevent them from attending social activities (Culley et al., 2013b).

The persistent physiological symptoms and pain caused by endometriosis often has repercussions on the individual's intimate relationships and family life. Dyspareunia, in particular, has adverse implications on women's sexuality and relationships, ultimately affecting their social lives, mental wellbeing and QOL (Schick et al., 2022). Women often avoid occasions to meet new partners as they feel fear and shame about being a potential burden to their new partners (Van Stein et al., 2023). Anticipating how to disclose endometriosis and the painful symptoms they experience can also cause women to feel embarrassed, inadequate and guilty, increasing their levels of stress, as well as creating barriers for themselves to forming new relationships and finding intimate partners. Moreover, the negative impacts of the physiological symptoms of endometriosis such as dyspareunia and infertility can cause strain and contribute to a relationship breakdown (Culley et al., 2013a). Dyspareunia and chronic pain have been found to have negative impacts on sex life, affecting between 33.5-71% of women living with endometriosis (Culley et al., 2013b). It is common for women who experience dyspareunia to avoid or limit sexual intercourse due to the pain, but it is also not uncommon for women to endure dyspareunia due to their desire for pregnancy or reluctance to let endometriosis affect yet another aspect of their life, such as their sexual functioning, sexual QOL and intimacy in their relationship with a partner (Culley et al., 2013b). In previous studies, women with endometriosis have reported losing a partner due to reasons such as sexual distress and stressful and strenuous fertility treatments (Van Stein et al., 2023). For a woman who prioritises being a mother, difficulty conceiving can negatively impact their mental health and self-esteem, which in turn can also affect the dynamics in their relationship

## ENDOMETRIOSIS & YOGA

with a partner, an example of how the biological, social and psychological factors influence each other and intertwine to create the complex perception of pain, as proposed by the biopsychosocial model.

Social domains can be influenced by endometriosis and its symptoms but at the same time, social factors can also have an influence in the individual's perception and experience of endometriosis-associated pain. Kalfas et al. (2022) stated that social and interpersonal factors play just as much of an important role in shaping the individual's experience of "physiological and psychological outcomes in persistent pain" (p. 1842). For example, being in a stable relationship and having greater marital satisfaction has been associated with improved mental health and a more positive outlook on one's own QOL (Kalfas et al., 2022). Endometriosis can affect both partners in a relationship and as they are interdependent in emotional and psychological response to endometriosis, it would be appropriate to involve the patient's partner when looking at helpful coping strategies for endometriosis and endometriosis-pain. This is to increase social support, improve mental health and QOL, and enhance relational dynamics, ultimately improving the patient's perception of pain (Van Stein et al., 2023). Strengthening the patient's intimate and other personal relationships (e.g., family, friends) can increase their satisfaction in the social domain and improve perceived QOL, helping to decrease their pain intensity level (Márki et al., 2017).

The biopsychosocial approach acknowledges that the individual should be considered holistically through looking at various domains in their lives, and that particularly in the social domain, it has been highlighted how endometriosis can impact the individual's relationships, work life and ability to socialise. In this approach, pain is ideally treated holistically with pain medications, support, and therapies to ensure overall well-being. Hormonal medication and surgery may be suggested to patients for pain management and treatment, as the biopsychosocial model still believes that endometriosis and endometriosis pain has some physiological origins (Smrdu, 2022). However, the biopsychosocial model acknowledges that endometriosis impacts and is impacted by various factors besides just the physiological, and thus propose that holistic interventions which promote "comprehensive, long-term multidisciplinary patient-focused care (gynaecologists, physicians, psychologists), with effective communication between treatment providers" (Van Niekerk et al., 2022, p. 5) may be effective in not only reducing pain but also improve the patient's psychological wellbeing and QOL. Also understanding that endometriosis can affect the individual's social life and relationship with others (Schick et al., 2022), the biopsychosocial approach states that pain management methods and treatment should incorporate and be collaborated with both the patient and those they have close relationships with, such as their

partners or family (Culley et al., 2013a). Support groups for women living with endometriosis is also suggested, as giving the possibility to relate and share information with those with similar experiences can increase social support (Schick et al., 2022), creating a positive impact on their social domain, helping them to cope with the pain, and improve their QOL.

### *Enactive Approach*

In some ways, the enactive approach is similar to the biopsychosocial model. The biopsychosocial model emphasises that pain needs to be analysed also through non-physiological factors and enactivism also recognises that there are elements beyond the physiological which influence an individual's perception of pain (Bever et al., 2016). Enactivism however, focuses on experience (Craig & MacKenzie, 2021). The enactive belief lies in cognitive science, supporting the ideology that cognition arises through the body's interaction and experience with its environment (De Haan, 2021). In enactivism, an individual's environment and their being react and influence one another, and there is mutual interaction (Schmidt, 2022). It emphasises on the interactions of the mind, body, and environment and that cognition does not occur solely in the head. Human beings are conscious, self-organising agents that sustain themselves through constant exchange and interaction with their environment (De Haan, 2021). Individuals need to make sense of their environment in order to live. The body physically experiences, the mind experiences through sense-making.

The 4Es of cognition is a concept concerning pain within the enactive approach that supports the idea that cognition is (1) embodied, (2) embedded, (3) enacted and (4) extended (Carney, 2020). Stilwell and Harman (2019) extended this to 5E however, adding the term 'emotive', as they believe that this domain "appreciates the first-person experience of pain, and avoids the trichotomization or dichotomization of pain that is common when clinicians apply the biopsychosocial model" (p. 644). These elements of the enactive approach are dependent of one another and have an intertwining dynamic, an aspect that the biopsychosocial model is criticised to be missing between the biological, psychological and social factors of the model (Aftab & Nielsen, 2021). In this approach, pain is analysed as a mind-body-world process that is relative and subjective.

Support for the enactive approach comes from its acknowledgment that the individual, as a whole, is all connected- holistically, their brain is connected to their body and the body is connected to their world (Stilwell & Harman, 2019). This approach can be praised for viewing the individual as autonomous beings, creating meaning and perception themselves through cognitive processing

and interaction with their environment. On the other hand, criticisms for the enactive approach question whether this theory can really claim that the individual (in how they are presented in this approach) really has autonomy. The individual in the enactive approach is compared to an organism, a living thing that requires enabling conditions to occur in order for the organism itself to function and process (Di Paolo & Thompson, 2014). If an individual is the organism and the environment is an enabling condition that is required to exist in order for the individual to generate cognitive process, create perceptions and survive, if the environment is taken away, would the individual still be considered autonomous if they are unable to operate? In other words, taking away the individual's external environment, which is a crucial element in interaction and therefore sense-making and cognition, it can be argued that the individual cannot exist by itself and sustain itself, taking away its autonomy (Di Paolo & Thompson, 2014).

*Enactive Approach & Endometriosis Pain.* Pain experience according to the enactivist approach, such as that of endometriosis-induced pain, differs across each individual and their experience is dependent on how they make sense of their environment, how they adapt to changes in their environment, and their sociocultural background (e.g., ethnicity, gender, religion) (De Haan, 2021; Miyahara, 2021). In relation to endometriosis-associated pain, the enactivist approach considers the individual's pain experience to be fluid, a process that is constantly changing with the fluctuations of dynamisms and interactions between the individual and their environment (Coninx & Stilwell, 2021). In this sense, a woman's pain and experience with endometriosis is ever-changing, as it is how they relate and make sense of their environment, their view of themselves in the situation and the world.

Coninx and Stilwell (2021) illustrate the concept of 'field of affordances', which is the process of how an individual evaluates action possibilities (affordances) in relation to their relevance to the specific situation and to themselves. Affordances are evaluated in terms of 'mineness', a concept that reflects how meaningful or important an affordance is to the individual, with stronger affordance mineness indicating a more profound interaction between the individual and the world, and a lesser mineness indicating an absence of such intimate relation and feelings of isolation or disengagement (Coninx & Stilwell, 2021). This concept of affordance and mineness is pertinent to understand the enactivist view on endometriosis pain. The sensory feeling of pain induced by endometriosis can affect various aspects in the individual's life, such as their mental health in respect to their view of themselves and stance in the world, ability to exercise daily activities, and their relationships in and ability to fulfil their roles in different societal contexts (e.g., professional, familial, cultural) (Coninx & Stilwell, 2021; Singh et al., 2018). These negative

implications that endometriosis has on the individual disrupts the interaction and relationship between body and world, preventing the individual to be able to physically carry out actions and activities, causing them to view their bodies as broken and creating a distorted view of themselves (Singh et al., 2018). Unable to interact with the world as their true self due to the experience of persistent pain, the individual encounters feelings of detachment as they then become incapable of interacting with and being embodied in their environment, perceiving their endometriosis and experience of pain as an affordance with lesser mineness and viewing their bodies as obstacles (Coninx & Stilwell, 2021). In accordance with the enactivist belief that the body is “crucial for cognition” (Smrdu, 2022, p. 13), this inability of the individual to engage and connect with their environment and social contexts due to painful endometriosis symptoms is a major aspect in shaping the individual’s perception of pain. Viewing their pain as a burden, this cognition can affect and be affected by how the individual physically interacts with their environment, creating a cycle.

Pain management within this model focuses on the cognition and the individual’s ability to control, monitor and alter their thinking. The enactivist model views the individual as autonomous beings who are capable of and responsible for making sense of their environment and experience (Smrdu, 2022). Thus, the enactivist perspective believes that treatment of patients should focus on recognising them as autonomous beings rather than viewing them as a set of symptoms (Popova & Raczaszek-Leonardi, 2020). The enactivist approach adopts a holistic stance to pain management and treatment of endometriosis, acknowledging that all domains in the individual’s life and their interactions need to be taken into consideration, with further emphasis on the patient’s subjective experience (Coninx & Stilwell, 2021). The enactivist approach proposes that treatment should be to guide patients to improve their interactions in the world (Coninx & Stilwell, 2021). In relation to endometriosis and pain management, the enactivist model advocates for helping patients to change their perceptions of pain, to help them to better connect with their body, assist them to accept and appreciate their experiences, and to help them view their body as “no longer the intruding object of attention and the source of alienation or isolation” (Coninx & Stilwell, 2021, p. 7854).

Like the biopsychosocial model, the enactivist approach to pain management is more so focused on providing the tools to the patient to help them change their perspectives on their experience and improving their ways of sense-making in order for them to have reductions in pain (Smrdu, 2022). Medication may still be suggested or provided to patients, however, cognition-focused therapies such as CBT are methods believed by the enactivist approach that obtain a deeper understanding of the individual (Coninx & Stilwell, 2021), their experiences and the domains impacted by endometriosis, which in turn can provide for a more individualistic, and therefore more

## ENDOMETRIOSIS & YOGA

effective form of pain management for endometriosis. Nevertheless, much like the other theoretical approaches to endometriosis pain management, none of the methods advocated by the enactivist approach have been proven to be definitively effective in reducing pain or eliminating endometriosis itself.

### *Feminist Theory*

To analyse how endometriosis and endometriosis-related pain came to be portrayed now, an analysis of earlier scientific thinking and historical conceptions of the endometriosis and menstruation is useful. ‘Hysteria’ was a disorder considered to be specific to women that was developed in the around 5th Century BC by Hippocrates (Tasca et al., 2012). The disorder was believed by Greek physicians to have scientific and spiritual causes, thought to be a misfortune brought about from the Gods, causing wombs to wander and causing disease (Guidone, 2020). Hippocrates asserted that women’s bodies and uteruses would get sick if they were deprived of sex and inhibited from procreation, claiming that this ‘dissatisfaction’ of the uterus caused it to wander and thus cause illness and disorders in women (Tasca et al., 2012). Characteristics of hysteria included anxiety, tremors, chronic pain and suffocation (Tasca et al., 2012; Medeiros De Bustos et al., 2014). Hysteria was suggested by physicians in this era as a symptom of menstruation and those who displayed any form of hysterical symptoms would be put away in confinement supposedly for the safety of everyone else in the community (Guidone, 2020).

Around mid-19<sup>th</sup> Century, negative gendered-stigmatisation around menstruation continued, whereby connotations surrounding physical and psychological illness were attached to menstruation and it was thought that women who menstruated had problems with infertility (Hudson, 2022). Similarities between hysteria and endometriosis have been found, such as that both conditions generate behavioural and psychological disturbances due to medical implications in the uterus, and that due to gendered and misogynistic stigmatisation attached to them, the conditions have been “systematically and historically dismissed” (Hudson, 2022, p. 22). Looking at historical contexts and how women’s health was viewed then through a patriarchal societal lens, this provides explanation of how contemporary ignorance and lack of knowledge towards menstruation and conditions such as endometriosis exist, as this dismissive attitude has been imprinted across a long timeline of historical contexts.

As the aetiology of endometriosis is still unknown, many beliefs surrounding the development of the condition also surface, some of them having underlying sexist ideologies. From around the 1960s up until the 1990s, endometriosis was labelled a ‘career woman’s’ disease, with

many medical professionals proclaiming that women who had children at an older age were more likely to develop endometriosis, and would advise women to get pregnant to reduce their chances of developing the condition and reduce their symptoms if they already had endometriosis (Hudson, 2022). For clinicians to advise their female patients to get pregnant without having definitive evidence that pregnancy is an effective intervention, is not only very misleading but also very misogynistic. To have advised pregnancy for patients, the clinicians can be criticised as practicing with the influence of the sociohistorical convictions of gendered roles, pushing for their patients to basically conform to society's expectations of a woman's role (Cole et al., 2021).

Additionally, it was also a historical belief that young girls could not develop endometriosis (Hudson et al., 2022). In contemporary science, it is now understood that adolescents can develop endometriosis (Bush et al., 2017). Societal stigmatisation surrounding menstruation and endometriosis symptoms still currently exist in our society and are some common factors as to why young girls avoid seeking medical advice from primary care providers (Gupta et al., 2018). Young girls perceive the notion that talking about menstruation and the female anatomy is considered taboo and that period-talk is considered 'gross', and it is this stigma prevents girls seeking help or having conversations about endometriosis symptoms (Gupta et al., 2018). It was a common opinion amongst adolescent girls in a U.S. study that endometriosis and mental health were both perceived as less taken seriously and less believed by their primary health care providers, feeling judged and thus the need to conceal their symptoms and avoid discussing their symptoms and pain altogether, as they feel that they will just be dismissed anyway (Gupta et al., 2018). The cultural stigmatisation of menstruation as a taboo topic and something to stay silent about is a serious barrier that prevents them from pursuing medical advice about their endometriosis symptoms and endometriosis pain (Gupta et al., 2018).

It is imperative to make changes to our society's mindset about menstruation and women's health in order for women and young girls to be able to openly discuss and seek help regarding any issues they may be experiencing with menstruation, such as endometriosis pain and symptoms, so that they can then receive the appropriate medical attention they require.

### **“Your Pain, Your Responsibility”**

With the lack of understanding around endometriosis, women's lived experiences of the condition such as perceived pain often get dismissed, questioning the legitimacy of their experiences and giving them the impression that they are to be accountable for their own illnesses (Kempner, 2014). Reluctance by medical professionals to diagnose and provide treatment is a cause

in this diagnostic delay, as clinicians rely too heavily on identifying and categorising the endometriosis symptoms to those according to classification systems such as the ASRM (Young et al., 2020; Hudson et al., 2022). The focus of medical classifications systems such as the ASRM is on the physiological characteristics of endometriosis do not take into consideration “women’s embodied symptoms” (Hudson et al., 2022, p. 24). The lack of commonality between the symptoms in the classification system and women’s lived experiences have yielded doctors to demonstrate a more dismissive attitude towards diagnosing women, leaving women to feel that they are ignored and doubted when they present with endometriosis symptoms of primary health care (Hudson et al., 2022).

Women who experience endometriosis-related pain can feel compelled to practice self-silencing as a coping strategy to manage their pain by themselves, feeling hopeless as their symptoms are dismissed, and that they are left to deal with the symptoms without any treatment (Cole et al., 2021). Self-silencing is also evident when women avoid speaking up in their relationships to avoid conflict and maintain their various roles in the relationships (e.g., role as a good partner, mother, daughter, etc.) (Cole et al., 2021). The ‘quick-to-dismiss’ attitude by health care professionals can be criticised as being not only due to their lack of specialised knowledge in endometriosis and gynaecology (Grundström et al., 2016), but also reflects the outcome of historical constructs associated with menstruation and women’s health. The negative consequence to this is that women can feel undermined when they present with endometriosis symptoms when seeking for a diagnosis, and can feel that they are not taken seriously by their clinicians.

In the management of endometriosis symptoms and its treatments, Young et al., (2018) found that it was common for health care professionals to prioritise heteronormative reproduction, considering conservative forms of treatment that do not hinder the woman’s fertility. This can be very problematic, as medical professionals assume based on a person’s biological sex beliefs on childbearing, instead of considering that the individual may instead alternatively prioritise pain relief and quality of life over fertility. This view can cause women to feel that they have failed in their role as a ‘woman’, which can have negative implications on their self-esteem and feelings of self-worth (Cole et al., 2021). As there is currently no cure for endometriosis, the frontline treatment for pain relief and managing endometriosis symptoms is hormonal medication, such as oral contraceptives (Ellis et al., 2022; NICE, 2017). The complicated matter with endometriosis treatments such as hormonal medication, is that they can inhibit fertility and women are then forced to choose between either prioritising symptom relief or their fertility (Culley et al., 2013a).

For people that have endometriosis, each individual should have the right to choose what they prioritise and be given the appropriate form of treatment that matches their decision. In contemporary science and medical field, full understanding and knowledge of definitive treatments for endometriosis is still lacking, and this can be criticised as taking away some notion of women's complete rights to be able to make this decision.

### **Theoretical Perspective Adopted in This Research**

The biopsychosocial approach will be implemented in this research, as I consider the biological, psychological and social factors to get a better understanding of the magnitude of impact that endometriosis and endometriosis-induced pain has on women, and how these factors influence and are influenced by endometriosis to shape the individual's perception and experience of pain. The biopsychosocial model views the individual as a whole interconnected being, taking into consideration the dynamism of the biological, psychological and social factors (Bever et al., 2016). Analysing the individual through a holistic lens unlike the biomedical model, the biopsychosocial recognises that by taking into consideration these other non-physiological components in a person's life, insight into how the individual lives with and responds to endometriosis and its symptoms is grasped (Bever et al., 2016). Somatically, the individual is impacted by endometriosis, however, other aspects in their lives are impacted also, such as their mental health and social functioning, ultimately having negative implications on their perceived QOL (Culley et al., 2013b). Acknowledging that women's lives are impacted in other ways besides just physiologically, I believe that this will help in attaining a better understanding of their perceptions and experience with pain, endometriosis and their QOL. The biopsychosocial model will be used to explore the various domains in order to get a better understanding of the patient's perception and experience of endometriosis-induced pain in all aspects of life.

### **QOL in the Context of Aotearoa**

The WHO states that QOL is defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (2012, p. 6). This definition demonstrates that how a person views their QOL is determined by how they evaluate their current positions in different domains, in comparison to the goals and standards they have set for themselves in these domains, as well as where they wish to be. When looking specifically at endometriosis QOL, the domains vary across different questionnaires, however, the common domains assessed are usually physical health, psychological wellbeing, self-image, social support, emotional role functioning, sexuality, work,

and feelings about infertility (Oxford University Innovation, 2016; Van Poll et al., 2020). These domains are commonly referenced when analysing the QOL of women who have endometriosis as these domains represent the various aspects in the women's lives that are adversely affected by the condition and its symptoms. Studies have highlighted the importance and relevance of analysing QOL when investigating the impacts of endometriosis and endometriosis-associated pain on women. Missmer et al. (2021) illustrate that endometriosis can have long-term negative implications to a woman's life and all different aspects within it, such as creating obstacles for them in achieving their goals, forming stable relationships and starting a family. It is imperative then to analyse the various domains in their lives to see how they are affected by endometriosis and how it has influenced their perceived QOL, as endometriosis impacts women over a long period of time, influencing how they respond to life-changing and ultimately shaping their self-perception on QOL.

When talking about QOL in health care, it is often regarded as how a disease or symptoms of the disease affects the individual through various aspects in their lives (Ruszala et al., 2022). In relation to endometriosis, aspects that are commonly referred to as being affected by endometriosis are social support, self-image, relationships, career, treatment accessibility, and infertility (Ruszala et al., 2022). Thus, when analysing the QOL of women with endometriosis, the domains frequently evaluated to assess the magnitude of impact of endometriosis are physical and social functioning, bodily pain, mental wellbeing, emotion regulation, self-image, control and powerlessness, social support, work, relationship with children, sexual functioning/relationship, and feelings about treatment and infertility (Van Niekerk et al., 2022; Oxford University Innovation; 2016).

The components associated with 'quality of life' are slightly varied in Aotearoa, as Māori models of health are acknowledged and implemented throughout health care systems. 'Te whare tapa whā' is a model that is commonly applied in health care to increase understanding of Māori health and wellbeing (Ministry of Health, 2017). Te whare tapa whā is an indigenous model of health which was created to tailor to the holistic values and principles of Māori, used by Māori and non-Māori practitioners to increase awareness and obtain a better understanding of the significant domains which are attributed to Māori health and wellbeing (Maidment, 2020). In this model, health and wellbeing is portrayed as a wharenuī (meeting house) with four walls, each wall representing a domain that is important for wellbeing (Tassell et al., 2012). The walls (or domains) are taha tinana (physical health), taha wairua (spirituality), taha whānau (family), and taha hinengaro (mental health & emotions), and each of these domains are viewed as foundations essential in maintaining the structure of the wharenuī, each dimension holding equal importance to establish balance and support stability in Māori health and wellbeing, (Tassell et al., 2012; Mental

## ENDOMETRIOSIS & YOGA

Health Foundation, 2023). According to this model, when all of these four walls (domains) are in balance, the individual will thrive, but if the individual is lacking in any of these foundations or any of the domains are ‘damaged’, this can signify imbalance in the person’s health or wellbeing (Mental Health Foundation, 2023).

The te whare tapa whā model can be conceptualised as somewhat of an extension of the biopsychosocial approach, acknowledging the importance and influence that biological (tinana), psychological (hinengaro) and social (such as whānau) factors have in shaping the individual’s wellbeing. However, the te whare tapa whā model also includes wairua (spirituality), a notion that holds relevance and should be considered when working with Māori. The te whare tapa whā model can also be viewed as having similar features with the enactive model in terms of valuing interconnectedness acknowledging the value of one’s relationship with their environment (Maiese, 2014; Maidment, 2020). However, the enactive approach puts more prominence on cognitive sense-making and experience, highlighting interconnectedness through more the mind, body and experience (Maiese, 2014), whereas the te whare tapa whā model adopts mindfulness in the relationship of the factors, associating interconnectedness between the mind, body and spirit (Maidment, 2020). Moreover, the te whare tapa whā model demonstrates similarity between the other theoretical standpoints of pain such as the biopsychosocial and enactive models, establishing its adaptability to be used across different fields including health care and mental health, showing appropriateness in application to the topic of endometriosis.

In relation to endometriosis, the te whare tapa whā model is relevant to use by practitioners, as the four domains (tinana, wairua, whānau, and hinengaro) are believed to be intertwining aspects that can be negatively impacted by living with endometriosis, and that having these domains ‘damaged’ can influence how the individual experiences and responds to endometriosis and endometriosis-associated pain, as well as shape their perception on their QOL or life satisfaction (Wyeth et al., 2013). For example, a woman living with endometriosis can experience physiological changes due to endometriosis such as CPP, dysmenorrhea and infertility (Poordast et al., 2022), affecting her physical health (tinana). She may experience negative feelings, such as depression or anxiety due to pain occurrence (Ruszala et al., 2022), affecting her mental health (hinengaro). Social isolation and having issues with relationships is also common to see amongst women living with endometriosis (Van Stein et al., 2023), such as with family (whānau) and wider networks. While there is indication to support the idea that the te whare tapa whā model may be an appropriate concept to use in analysing QOL of endometriosis patients in Aotearoa, extensive research still needs to be executed to further strengthen and prove this notion.

### **QOL Domains in the Context of Endometriosis**

The endometriosis health frameworks evaluating QOL or HRQoL in endometriotic patients encompass various aspects which fall under broader biological, psychological and social domains (Jia et al., 2012). Prior to outlining the frequently used endometriosis questionnaires and the domains incorporated within them, clear justification between the terms ‘QOL’ and ‘HRQoL’ must first be distinguished. QOL and HRQoL are sometimes used interchangeably throughout literature and as the concept of HRQoL constitutes both notions, health and QOL, differentiating it from QOL can be complex (Jia et al., 2012). As previously mentioned, QOL can be understood as an individual’s subjective perception and evaluation of their current positions in different domains of their lives, in relation to their goals, expectations and standards (WHO, 2012). On the contrary, the definition for HRQoL would be better understood as an individual’s subjective understanding of how a specific condition (in this case endometriosis) impacts the various domains in their lives, shaping their perceived QoL. In other words, HRQoL is essentially an individual’s QOL but specifically evaluated in relation to an illness (e.g., endometriosis). Arguably, one’s perceived HRQoL and perceived QOL can be viewed as being the same, as an illness or symptom of an illness, such as pain, can filter through all aspects of an individual’s life. This makes it very difficult to justify how QOL can be perceived in isolation to the illness when the illness (i.e., endometriosis) prevails greatly on the individual’s life. The term ‘QOL’ will be used for simplicity sake throughout this research but references HRQoL in endometriotic women.

The Endometriosis Health Profile (EHP-30; shortened 5-question version is the EHP-5) is a validated questionnaire that measures the impact of endometriosis on women’s HRQoL (Hansen et al., 2021). The domains included for evaluation in the EHP-30 are those that are impacted specifically by endometriosis and which have been deemed important by women to their QOL. In the core form, it consists of 30 questions over five domains (pain, control and powerlessness, social support (or lack of), emotional wellbeing and self-image), whereas the short-form (EHP-5) consists of one item from each of these five scales (Oxford University Innovation, 2016). Additionally, there are six modular scales comprising of 23 questions which are optional to use alongside the core five scales, and these are domains which may not be applicable to every woman living with endometriosis. These six supplementary scales are: work (5 items), relationship with child/children (2 items), sexual relationship (5 items), feelings towards medical profession (4 items), feelings about treatment (3 items), and feelings towards infertility (4 items) (Oxford University Innovation, 2016; Poordast et al., 2022). Questions in the EHP are asked in regards to the patients’ experiences with endometriosis within the last four weeks and are answered using a 5-point Likert scale where

## ENDOMETRIOSIS & YOGA

0=never, 1=rarely, 2=sometimes, 3=often, and 4=always (Taylor et al., 2020). The EHP-30 is the only condition-specific measure for endometriosis QOL that has been extensively validated (Jia et al., 2012), often using the SF-36 as a gold standard to assess convergent validity, in which a strong correlation was found between the two questionnaires (Bourdel et al., 2019).

Coinciding with the belief that endometriosis and its impacts on QOL should be analysed through a holistic lens, the evaluation of the efficacy of yoga as a form of pain management for endometriosis in this research would be appropriate to be analysed through my endometriosis health questionnaire (having a similar structure and framework as the EHP-30). This is because yoga is seen as a practice that presents a holistic viewpoint, focusing on improving physical, psychological and overall wellbeing (Doulatabad et al., 2013).

### **Yoga for Pain Management**

Yoga can be characterized as an ancient holistic practice that originated in India over 4000 years ago which combines forms of exercise and mind-body awareness (Holtzman & Beggs, 2013). Yoga is comprised of several elements in practice- postures (asanas), breathing techniques (pranayama), and relaxation and meditation (dhyana) (Holtzman & Beggs, 2013). The aims of yoga are to establish and improve overall wellbeing by creating a strong and balanced relationship between the mind, body, and spirit through a combination of mindfulness methods and physical activity (Doulatabad et al., 2013). The practice and teachings of yoga are affiliated with the concept of QOL, as it views the person from a holistic perspective, highlighting that a sense of health and wellbeing is achieved through finding harmony and working on various domains in the person's life such as psychological, physical and wairua (spirituality). Not all women living with endometriosis want to use or find medical forms of pain management effective and may try other methods which are non-medical. Yoga has been more recently implemented in our society as an alternative practice in health care and due to the limited effectiveness of current medical pain management and treatment method for endometriosis, women are taking matters into their own hands in the to cope with their pain. In a survey of Australian women with endometriosis, it was found that 35% of the participants practice yoga to help with their endometriosis pain (Armour et al., 2019). Specifically with endometriosis, pain is a common symptom that negatively affects women's perceived QOL (Kashi et al., 2018). Comprehensive forms of endometriosis pain management such as yoga, that focus on emotion regulation strategies, negative emotion reduction, sustain work and relationships, and reducing pain (holistic models) should be implemented in order to increase satisfaction in these various domains and improve the individual's perception of their QOL.

Empirical evidence has surfaced regarding the benefits of yoga on psychological and physical health. The asanas (poses) and physical aspects such as stretching, strengthening, balancing and aerobic components have been found to generate blood flow and circulation throughout the body by increasing respiratory intake through such movements, relaxing muscle tension and easing pain (Goncalves et al., 2016). Moving the body during yoga has also been found to bring about improved mobility, flexibility, and posture, all of which are also factors that contribute to pain reduction (Keosaian et al., 2016). Previous studies on the impacts of yoga on psychological functioning and wellbeing in individuals living with chronic pain conditions have found support for yoga in improving mental health and alleviating pain. Yoga has suggested improvements in pain management and stress responses through the regulation of the hypothalamic-pituitary-adrenal (HPA) axis, activating the autonomic nervous system (ANS), and improving the immune system (Goncalves et al., 2017; McCall, 2013). In a study by Keosaian et al. (2016), efficacy of yoga as pain management for chronic low back pain was evaluated and the researchers found immense psychological effects of yoga on the participants. Patients reported that their overall mindset became more positive, gaining an increase in their ability to self-regulate their pain, having an improved mood and felt a higher sense of empowerment after practicing yoga for 12 weeks, helping them to reduce the pain. The relaxation techniques help to lower cortisol levels, decreasing stress and anxiety levels, effects which Doulatabad et al. (2013) found in their study of yoga as pain management for multiple sclerosis, improving the participants' QOL scores after 3 months of practicing yoga.

Nevertheless, in spite of showing positive effects to other illnesses, research surrounding efficacy of yoga on endometriosis pain is still sparse. Goncalves et al.'s (2016) and (2017) studies were done simultaneously and are the only studies within the current literature that specifically analysed the effects of (Hatha) yoga on endometriosis patients, examining its suitability in pain management and its impacts on the domains in the participants' lives. Benefits of yoga were seen in psychological domains, in that the women reported that the relaxation and breathing techniques helped them to reflect on their pain, regulate their mental and emotional states, and use self-control to reduce the pain (Goncalves et al., 2017). At the end of the study, endometriosis patients established lower chronic pain levels as well as improved QOL scores in various domains such as pain, control and powerlessness, mental wellbeing, self-image, and social support (Goncalves et al., 2017). Although global and New Zealand research is still limited around yoga as pain management for endometriosis, there is some support that shows indication for its appropriateness and

effectiveness in reducing endometriosis-related pain experience and improving QOL, further highlighting the need for more extensive research to be held in this field.

### ***Mind-Body Intervention for Endometriosis Pain Management***

As research is lacking on yoga as a form of pain management for endometriosis, evaluation should then be aimed at the efficacy of the components which make up yoga and their impacts on reducing endometriosis-associated pain. Mind-body intervention such as mindfulness is one aspect of yoga that focuses on psychological and emotional regulation. Mindfulness techniques include those such as deep-breathing exercises, visualization or guided imagery, meditation, and relaxation (Li et al., 2023). Mindfulness involves emotion regulation through observation of inner experiences and showing awareness of these inner experiences without judgment and reactivity, helping to improve one's coping strategies and reduce avoidance, beneficial in the management and alleviation of pain (Hansen et al., 2017; Evans et al., 2019).

In researching mindfulness and endometriosis pain, studies have found mind-body interventions such as mindfulness to help improve levels of pelvic pain, anxiety, depression, stress, and fatigue (Evans et al., 2019). In Kold et al.'s (2012) study performed in 2007 on mindfulness intervention impacts on endometriosis, patients showed improvements in their SF-36 and EHP-30 scores after finishing the 10 weeks of mindfulness intervention, establishing improved QOL upon completion of the study. During a 6-year follow-up conducted in 2013 by Hansen et al. (2017), 90% of the participants still used the mindfulness techniques taught to them from the 2007 study. Patients completed the SF-36 and EHP-30 again and the researchers found that the significant positive improvements in the 2007 study had lasting effects as they remained in multiple domains in the EHP-30 (pain, control and powerlessness, emotional wellbeing, and social support), and the improvements in the 8 domains of the SF-36 also remained throughout the 6 years (Hansen et al., 2017). These findings suggest that participants found the mindfulness intervention effective in alleviating their endometriosis pain and improving their QOL as they continued to practice the techniques years after completion of the study, which then maintained a positive long-lasting effect on the various domains in their lives and QOL. Findings such as these by Evans et al. (2019) and Hansen et al. (2017) provide support for the use of mind-body interventions in reducing endometriosis pain, as well as having beneficence in other non-physiological aspects of life which are also attributed to having influence in shaping overall perceived QOL. A holistic practice, mindfulness supports the ideology praised by the biopsychosocial approach in that endometriosis pain, its experience and effects in wider functioning are determined by various physiological, psychological, and social factors (Evans et al., 2019). While there is some evidence in the currently

## ENDOMETRIOSIS & YOGA

literature that indicates appropriate use for mind-body intervention in endometriosis pain management, research is still limited due to the classification of mindfulness as an alternative non-medical form of pain management, creating reluctance by researchers to study the concept. Mindfulness needs to be more acknowledged by researchers and pain needs to be recognised through a holistic perspective that extends physiology so that more psychological and mind-body interventions can be implemented for pain management, as past findings suggest there is support for efficacy in mindfulness for endometriosis pain and this should be further studied extensively.

Nevertheless, as there is support for implementing mindfulness intervention for endometriosis pain management, there are also opposing views against mindfulness as a practice and arguments disapproving its ability in pain management. Mindfulness practice involves recognising and being aware of inner thoughts, sensations, and experiences, assisting the individual in their perceptions of themselves (Farias & Wikholm, 2016). Doing this within a therapeutic context with the guidance from a trained mental health clinician may bring about positive outcomes, however, if the person is doing it alone or is led by a non-professional, mindfulness may amplify negative inner problems and insecurities (Farias & Wikholm, 2016). For example, if an individual performs mindfulness techniques for their endometriosis but they may also have or have a predisposition to depression, mindfulness may cause the individual to focus on adverse thoughts, feelings, and trauma to arise, and they may then experience emotional difficulty, and perhaps heightened pain sensation. Furthermore, mindfulness requires focus and training, and may not be effective if the patient is not engaged or does not reach the state of consciousness required to achieve non-judgmental awareness of their inner experience (Banerjee et al., 2017; Farias & Wikholm, 2016), possibly causing a feeling of hopelessness and distress, impacting their psychological wellbeing.

Although there has been evidence to support mindfulness in improving psychological wellbeing through emotion regulation, obtaining a sense of autonomy, and breathing techniques (Evans et al., 2019), another question regarding its true effectiveness in managing endometriosis arises. Enhancing the psychological wellbeing of an endometriotic patient may be beneficial in improving their QOL, however, mindfulness does not target the physiological characteristics of endometriosis itself and thus the mindfulness practices can be argued as simply masking the symptoms and actual cause of endometriosis and pain. Again, research around mindfulness in general and specifically concerning its efficacy with endometriosis pain management is still very much lacking and definitive statements about its use for pain management should not be made until more extensive research can define its effectiveness/non-effectiveness.

### *Physical Activity & Exercise for Endometriosis Pain Management*

Another aspect to yoga is physical exercise, incorporated through asanas (poses), stretching and low intensity mind-body movements. Physical activity and exercise can be considered as having similar definitions, however physical activity can be more understood as bodily movements that require energy, whereas exercise can be characterised as physical activity that is performed to intentionally improve or maintain fitness (Tourny et al., 2023). There is currently no research found around this topic in New Zealand literature, however, there is more research surrounding the effects of physical activity and exercise on endometriosis (globally) compared to mindfulness intervention on endometriosis, although exploration within this topic is still scarce. The inflammatory characterisation of endometriosis causes heightened sensitisation to the affected organs, believed to be the cause of chronic pain (Tennfjord et al., 2021). Researchers theorise that physical activity and exercise can generate serotonin regulation, reduce nerve growth factor expression, and create anti-inflammatory effects through the release of myokines, all of which are factors which can help with reducing endometriosis-related pain and endometriotic lesion growth (Ensari et al., 2022). Exercise can also have positive impacts on psychological wellbeing, with past studies showing that exercise can increase one's ability to use coping strategies for endometriosis pain management, contributing factors to improved pain levels and QOL (Ensari et al., 2022). The support for physical activity and exercise to be effective forms of endometriosis pain management can be viewed as stemming from a more biomedical perspective, highlighting the physiological characteristics of endometriosis and its somatic effects on the body, with some adoption of the biopsychosocial model as well, in that physical activity can also bring about positive mental health and improved QOL.

Ensari et al. (2022) conducted an international study which analysed the impacts of physical activity and exercise patterns on endometriosis-related pain. The findings demonstrated that women who exercised at least three times per week were less likely to experience pain the following day, while those who exercised infrequently or none at all were more likely to report higher levels and larger increases of pain the day after exercise (Ensari et al., 2022). These outcomes support the idea that regular physical activity and exercise have positive impacts on pain caused by endometriosis. Furthermore, exercise has also been found to be a protective factor of other chronic conditions which have inflammatory characteristics just like endometriosis, such as type 2 diabetes and breast cancer (Tourny et al., 2023). Montenegro et al. (2019) analysed the effects of exercise on endometriosis by conducting their study on a rat sample. After 10 weeks, the rats were tested and researchers found those that exercised at least three times per week demonstrated significant reduction in their endometriotic lesion size compared to the rat groups that exercised only once per

week (Montenegro et al., 2019). The clear limitation of this study is that it is an animal study, not involving humans. Also, it is still unknown whether routine exercise and the reduction in lesion size improved pain level or not, as having non-human subjects, meant that they were unable to communicate to the researchers. Still, the findings by Montenegro et al. (2019) have provided some useful findings on the effects of regular exercise on endometriotic lesions. Additionally, the findings by Ensari et al. (2022) portraying the positive effects of regular exercise on endometriosis-related pain. These studies have brought about valuable associations between exercise, endometriosis, and endometriosis-induced pain, however, research is still limited in this area.

### **Conclusion**

The existing research suggests that yoga, a practice that combines mind-body intervention and physical activity, can be effective for endometriosis pain management. Yoga has been found to hold effectiveness in reducing pain in chronic pain conditions such as chronic low back pain and multiple sclerosis (Keosaian et al., 2016; Doulatabad et al., 2013), however as research surrounding yoga as pain management for endometriosis is very still scarce, yoga cannot yet be conclusively stated as being either adequate or insufficient for endometriosis pain. Studies evaluating the effectiveness of mindfulness and physical activity as pain endometriosis pain management demonstrated that there is some support for their use in reducing endometriosis-related pain and improving QOL (Kold et al., 2012; Hansen et al., 2017) . Mindfulness focuses on strengthening the individual's psychological domain by supplying tools for coping strategies and emotion regulation (Hansen et al., 2017), whilst the physical activity aspect helps individuals move their body in order to reduce the inflammatory elements of endometriosis, reducing the sensory feeling of pain (Ensari et al., 2022). The combination of mindfulness and physical activity practiced in yoga takes on a holistic, biopsychosocial approach, targeting to reduce pain and other symptoms through the psychological and physiological domains, and the improvements within these domains can then also help to enhance the social domain, all-in-all helping to improve the individual's perceived QOL. As there exists some supporting evidence for yoga as pain management for endometriosis, I will be implementing yoga in this research to try and discover my own findings, and in particular, in an Aotearoa setting with New Zealand women.

### Chapter Three: Methodology

This chapter begins with an outline of the philosophical stance incorporated in the research. The rest of the chapter discusses the procedure, ethics and analysis.

#### Critical Realism

A critical realist philosophical position was adopted in this research. The ontological belief of critical realism (CR) is that observable occurrences arise as a result of deeper structures and mechanisms which are constantly changing and prevail beneath the surface (Stutchbury, 2022). Critical Realism recognises that these influential mechanisms are not always observable but can be accessed to an extent through research. In CR, a reality is believed to exist independently of our thoughts or observations on it. For example, endometriosis can occur and develop within a woman's body independently whether or not it has been found or observed by the woman herself or by medical professionals.

Reality is viewed as being like an iceberg, consisting of many layers, most of which are invisible and cannot be seen on the surface. Reality is categorised into three layers: the 'empirical', 'actual', and the 'real'. The 'real' domain consists of structures and causal mechanisms which affect the other layers, generating experiences and events (Haigh et al., 2019). The 'real' level is unobservable (Zhang, 2023) and is at the very bottom of the iceberg. In relation to endometriosis, an individual's personal values, upbringing, societal conceptualisations surrounding women's health, endometriosis and pain, and cultural beliefs are some examples which can be described as causal mechanisms in the 'real' level. They are unseen factors which have powerful influence over the person and guide them to subconsciously behave or perceive the way they do. The 'actual' domain consists of experiences or phenomena that occur in the world which can (but may or may not be) observed by humans, and are activated by the underlying causal mechanisms in the 'real' level (Koopmans & Schiller, 2022; Stutchbury, 2022). The 'actual' level is just below the surface and can be investigated using qualitative methods to obtain a better understanding as to why such events occur. Such occurrences in the 'actual' level can be attributed to those such as women's experiences of their endometriosis-associated pain and the impacts of endometriosis on different domains in their lives and QOL. These circumstances commonly occur with endometriosis however, why they occur and the extents to which they occur are not fully understood and greater insight regarding these concepts can be attained through further research and observation. Finally, the 'empirical' domain consists of the individual's knowledge and sensed perceptions of events or effects that they have observed and experienced (Stutchbury, 2022; Haigh et al., 2019). The

empirical level is considered to be the visible part of the iceberg. In women living with endometriosis, the sensory of pain and other physiological symptoms of endometriosis can be considered as part of the 'empirical' level. This characterisation of endometriosis allows me to acknowledge that the physiological symptoms have been developed and agreed upon over the years through the communications, interactions, and observations (e.g., surgeries and examinations). The meanings attached to endometriosis are socially and subjectively constructed, as it depends on each person's journey with the illness, the physiological and psychological symptoms they experience, the impacts of endometriosis on various aspects of their lives, and how endometriosis is portrayed in the community (e.g., the education and social connotations around it).

This research was driven by a feminist framework to prioritise women's (participants) experiences to view endometriosis, its impacts, meanings and conceptions surrounding it, from a female point of view. The feminist theory holds the view that patriarchal ideology has shaped sociohistorical constructions of women and their bodies (Young et al., 2020). Feminist researchers argue that contemporary understandings of endometriosis (and lack thereof), have been shaped by this patriarchal view, ultimately affecting women's endometriosis journeys and healthcare experiences, such as through the misogynistic and gendered associations made towards women and their bodies by clinicians, diagnostic delays, dismissive attitudes towards women and their pain, and the inadequate medical knowledge surrounding endometriosis itself (Young et al., 2020).

Having a feminist theoretical perspective guided me to privilege the participants' voices and lived experiences, aspects which are commonly disregarded or dismissed throughout women's endometriosis journeys (e.g., by medical professionals, family, friends) (Kempner, 2014). I viewed the women as experts of their own lives, giving them voices to share their individual experiences with pain, endometriosis, and healthcare encounters. This helped me to discover how they manage their pain and other symptoms, and to obtain a deeper understanding of the impacts of endometriosis on various aspects of their lives and how this influences their perception of their QOL. As a researcher that holds feminist views and advocates for the voices of women to be heard, my role as a researcher was to ensure that I demonstrated care, collaboration and respect (Cole et al., 2021), and that I valued, understood and interpreted their stories accurately.

### **Reflexive Thematic Analysis**

Pain and endometriosis were the phenomena investigated in my research. Critical realism within this study was appropriate as I asked participants to rate their pain using a measure but also reflect on the subjectivity of their pain. Because of the research design which included measurement

and interview data, reflexive thematic analysis was seen to be an appropriate method of data analysis to use as it can allow for the exploration of people's subjective experiences of endometriosis and pain and allow me to consider the pain scale data, interviews, questionnaires and journal entries (RMIT, 2022). More specifically, I employed a reflexive thematic analysis and utilised my role as an active researcher by identifying, interpreting and analysing patterns and themes in the data (Byrne, 2022). Using a reflexive thematic analysis (RTA), my engagement to the data set was key. Being engaged throughout the analytical process meant that I had to be reflective and thoughtful of the data that was produced in the research, including exercising contemplative interpretation of patterns within the data, actively coding and finding themes in the data set (Byrne, 2022). RTA encourages the researcher to embrace subjectivity and reflexivity and consider these as notions beneficial and helpful in developing knowledge (Braun & Clarke, 2019). The shared emphases of subjectivity across CR further supports the appropriateness of using RTA as a method of data analysis for my research which focuses on individual experience and perspective of pain and endometriosis. I acknowledged that I could gain insight into people's personal experiences and that as a researcher I was also able to construct knowledge, therefore I had to stay mindful and reflexive throughout the data collection and analysis processes (Grogan et al., 2018).

### ***Reflexivity***

The research viewed participants as experts of their own lives, providing them with opportunities to define their own endometriosis and pain experiences (Hoss & Hynes, 2022). This can be seen throughout the research, such as that participants were asked open-ended questions in the semi-structured interviews and were advised that they were able to share as much or little information as they were comfortable with, giving them the freedom to discuss various topics related to endometriosis. A relationship between the researcher and the research is inevitable, and collaboration between the researcher and participants enables empowerment and therefore helps participants to take ownership of the project in their sharing of knowledge and truths (Karnilowicz et al., 2014). Acknowledging my subjectivity and potential biases, I practiced reflexivity throughout the research as well as in the analysis process, reflecting on how I am as a person and my values may have impacted the research aims, procedures and interpretations.

Executing qualitative research, I acknowledged that subjectivity was at the centre of my study. Subjectivity is valued in qualitative study and a researcher's subjective experience and perspective are inevitably intertwined with the research and its processes (Stenfors et al., 2020). Recognising this, reflexivity should be practiced by the researcher to demonstrate their ability to assess and make ethical decisions amid the existence of their subjectivity in the research and to

“account for how subjectivity shapes their inquiry,” (Olmos-Vega et al., 2022, p. 241). As a researcher, it was critical that I understood my role in the study (e.g., how the participants viewed me and my position as a researcher, the influence I had on the participants’ responses, my relationships with the participants, etc.) and that I reflected on this (Stenfors et al., 2020).

Reflexivity is a multifaceted practice which involved me having to consciously evaluate various personal, interpersonal, methodological and societal factors which influence how the study was conducted, how the participants responded and what information they shared, and how the data was collected and analysed (Olmos-Vega et al., 2022). Reflexivity, in line with the values of CR, embraces and values subjectivity. By reflecting upon my impact as a researcher and exploring the influence of my subjectivity and other personal, interpersonal, methodological and societal factors into the research, this increased the confirmability and transferability of my study and its findings (Olmos-Vega et al., 2022).

I practiced reflexivity throughout every step of the research so as to ensure that any pre-conceptions I had towards the research did not influence how data was collected, the execution of procedures and how information was interpreted. A major concern I had going into this research was my position and personal experience with endometriosis, and whether it would affect how I conducted the research. As qualitative research seeks to understand individual perceptions which are influenced by factors such as culture, personal beliefs and environment through interactions with participants, the researcher’s interpreted knowledge is their understanding of the participants’ accounts, a construct of the collaborative sharing of information and dynamic interactions with participants (Lisboa, 2018). In this way, it is contended that total objectivity is not possible. Understanding this stance, I acknowledge that my personal journey with endometriosis may have some influence as to how the research was structured, the ways in which data was collected and how it was interpreted. This became a strength and allowed me to become more reflexive and conscious of such potential biases at key points of the research process. I was particularly aware of this positionality as an insider during data analysis and spent time discussing this with my supervisor.

Also, I had to reflect on the research procedures themselves and whether the methods chosen to collect data would have any impact on how the participants provided information. I used face-to-face interviews with the participants: once before the research commenced to get a better understanding of their endometriosis history, and another interview once the research finished to find out about each participant’s experiences with the yoga and research. I decided to conduct face-to-face interviews to build a relationship (whakawhānaungatanga) and rapport with the participants

## ENDOMETRIOSIS & YOGA

(Pitama et al., 2017), and so that I could also share the details of the research (mōhio tanga) with the participants with less likelihood of misunderstanding through direct communication. I was mindful that interviews can possibly increase pressure for participants and lead them to disclose and share information which they thought were desirable for me, the researcher, and the research itself (Grogan et al., 2018).

### **Ethics**

In discussions with my supervisor, a full ethics application was deemed appropriate. This was because exploring participants' histories with endometriosis is personal and sensitive to nature, and also, I was asking them to commit to doing yoga. For participants to recall their experiences with endometriosis, their symptoms, and their medical journey, this had the potential to cause distress, embarrassment and discomfort. Human Ethics Application OM1 23/10 was approved by Massey University's Ohu Matatika 1 Committee.

For this project the specific ethical issues were concern for distress, autonomy, risk versus benefit, and cultural issues. To help minimise and manage distress, semi-structured interviews were held by myself, a female also living with endometriosis. The casual format of the interviews allowed the participants to guide the interview and provide details they were comfortable in sharing. I was able to understand and empathise about their situation and experiences, as well as share my own experiences. This helped the participants to feel more at ease and decrease distress, as they were sharing information with someone (me) who can mutually relate to them. Initially I had thought of having an inclusion criterion of being laparoscopically diagnosed with endometriosis. However, in most cases of endometriosis patients, even though sometimes endometriotic adhesions and cysts can be seen through ultrasound or MRI (Berker & Seval, 2015) and patients have been living with endometriosis symptoms, doctors may be reluctant to suggest laparoscopy. Hence for this reason, I decided to make the inclusion criteria as '*clinically diagnosed with endometriosis*', in that their diagnosis can be through other methods such as through ultrasound, transvaginal ultrasound and MRI, as well as laparoscopy.

The implementation of yoga practice was also a concern raised by the ethics committee, questioning whether yoga could escalate the participants' pain levels. To ensure that participants' safety and wellbeing were prioritised, during the phone screening process, participants were asked questions from the PAR-Q health screening questionnaire (Warburton et al., 2021), assessing whether they were of generally fit health to participate. I also informed the participants that involvement in the research was voluntary and they could withdraw at any point. If they

experienced any pain throughout the yoga sessions, the instructor would suggest an easier variation of the pose or exercise, and the participants also had the right to lie down, take a break or leave the class if they were in any discomfort or pain. Participants were also informed that if they were unable to attend a class (e.g., due to pain, other commitments, etc.) this would be understandable.

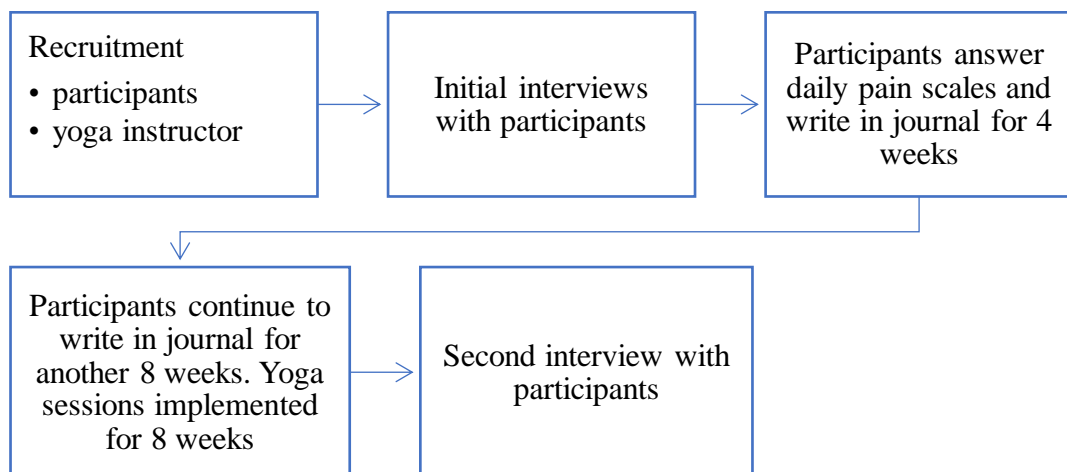
Lastly, cultural competency was another ethical consideration. My research was open to females of all ethnicities and backgrounds. To ensure that the research was conducted in a way that upheld the principles of the Treaty of Waitangi, I developed a cultural plan (Appendix A) to reflect upon should I have Māori participants. In the plan I outlined that the research and interview process would reflect Māori values and demonstrate a commitment to the principles of partnership, protection, and participation of Te Tiriti o Waitangi. In practice I did not have any Māori participants, but I used the same considerations with all my participants.

### Procedure

The procedure was somewhat complicated but it has been summarised in Figure 1. Each step is outlined in more detail below.

**Figure 1**

*Outline of Procedure Carried Out in Research*



### *Recruitment and Participants*

Firstly, I created two advertisements, one for the recruitment of the participants, and the other for the recruitment of a yoga instructor (Appendix B). The advertisement for participants included details of the research and inclusion criteria, whereas the advertisement for the yoga instructor simply described the research as studying the effectiveness of yoga in managing endometriosis pain, as well as including the inclusion criteria. Then, the advertisements were posted

on my Facebook and Instagram social media accounts, also posting them on various Facebook Auckland community pages that I was a part of, as well as the ‘Overheard @ Massey Albany University’ Facebook page. I also asked Endometriosis New Zealand for permission to promote my research and they agreed to share my advertisement.

Participants and interested yoga instructors responded to me via email, text message or social media. I corresponded by email and sent the participants the information sheets (Appendix C). If participants met the criteria and were interested in being part of the research, I then followed up by giving them a phone call to introduce myself, give background on the research aims and procedures, what the interview process would entail, and also asked them questions from the ‘Physical Activity Readiness’ (PAR-Q) health screening questionnaire (Appendix D). The PAR-Q questionnaire is used by medical and exercise professionals globally and within New Zealand to assess an individual’s fitness and identify whether they are of fit health to practice unsupervised exercise (NZREPs, 2014). Participants also needed to be feeling some level of pain regularly to be included in the research. Once confirmed they have no other serious medical conditions that would need signing off from their GP, we organised a date to conduct their initial interview and I emailed them the consent form (Appendix E) to read over before the interview.

My supervisor and I agreed that a maximum of 10 participants would allow for gathering rich and qualitative data (Vasileiou et al., 2018). A total of five women were selected who met the criteria and were able to attend the days organised for yoga. Demographic characteristics of participants are detailed in Table 1.

**Table 1**

*Participants’ Demographic Characteristics*

	Participants				
	<b>Miriam</b>	<b>Holly</b>	<b>Tessa</b>	<b>Sarah</b>	<b>Margaret</b>
Gender	Female	Female	Female	Female	Female
Age	26	23	30	32	35
Ethnicity	Iraqi	Pākehā	Hong Kong	Pākehā	Scottish-Indian
Occupation	Self-employed	Unemployed	Student	Student & PT nanny	Internal communications
Marital status	Married	Single	Single	Single	Married
Children	0	0	0	0	0

## ENDOMETRIOSIS & YOGA

	<b>Miriam</b>	<b>Holly</b>	<b>Tessa</b>	<b>Sarah</b>	<b>Margaret</b>
Time from symptom onset to diagnosis	7 years	8 years	3 years	12 years	21 years
Diagnostic method	Pelvic exam	Laparoscopy	Laparoscopy	Laparoscopy	Ultrasound
Stage of endometriosis	Unknown	Unknown	Unknown	3	4
Current medication / pain management methods	Mirena IUD, hot water bottle, pain killers	Mirena IUD, COC <sup>2</sup> pill, venlafaxine, Panadol, tramadol	Chinese herbal tea, hot water bottle	COC pill (Ginet)	Hot water bottle, over-the-counter painkillers
Surgical treatments	Laparoscopy	Laparoscopy (x2)	None	Laparoscopy	None
Other health conditions	None	Adenomyosis	None	PCOS <sup>3</sup>	None

Only participants Miriam, Tessa and Margaret partook in the yoga sessions and wrote in their journals until the research end date and received post-test interviews. Participants Holly and Sarah did not attend any yoga sessions and they only wrote in their journals up until they withdrew from the research. Inclusion criteria were: female aged between 18-50 years old, living in Auckland, clinically diagnosed with endometriosis, generally fit to practice yoga, and comfortable and willing to share endometriosis journey.

Out of the yoga instructors that expressed interest, I had selected one woman, Samantha, who had met the inclusion criteria and had the most flexibility in the days she was able to teach the sessions. Inclusion criteria were: qualified yoga instructor, able to teach two 60-minute yoga sessions per week for 8 weeks, able to teach a beginner form of yoga such as Hatha yoga, and must be living in Auckland. I arranged for a face-to-face informal meeting to get to know her better, her yoga background, and to give more details about the research and its aims and purposes. Prior to meeting with her, I emailed through a confidentiality agreement and behaviour guideline (Appendix F). During the meeting, we went over the procedures of the research, her experience with and attitude towards yoga, her plans for coordinating the yoga classes, and any other enquiries she may have had. She expressed that she would teach Hatha yoga, as it is a form of yoga that consists of

<sup>2</sup> Combined oral contraceptive pill (oestrogen and progesterone).

<sup>3</sup> Polycystic ovarian syndrome.

slower movements and focuses on breathing (Haryono et al., 2023), suitable for beginners and appropriate to apply to this research. She claimed that with a small group size of five participants, she would be able to communicate with them, and focus on each participant's needs and pain levels. I used my postgraduate research funding to give the yoga instructor a stipend for her time.

### *Participants' Initial Interviews*

The location of the initial interviews was determined by the participants. Four of the interviews were held in the participants' homes and one participant requested to have the interview at a group room in the Auckland University of Technology (AUT) library. Interviews were held with each participant separately. The interviews were semi-structured and conducted with a casual conversational structure. I created a rough guideline of the questions to ask the participants (e.g., making notes to bring up important details such as procedures, methods of data collection, right to withdrawal, etc.) as well as a safety plan for the interviews (Appendix G), but the topics discussed and the flow of the interviews themselves were guided by the nature of the conversation. I tried to create *whakawhānaungatanga* by introducing myself and sharing my endometriosis journey. This allowed me to build a connection and rapport with the participants, hoping to make them feel comfortable in also talking about their endometriosis journeys. This was followed by asking the participants some general questions regarding their age, ethnicity, and why they were interested in getting involved in the research. Following this, I asked the participants if they could tell me more about their personal experience with endometriosis, and in sharing the information, I would respond with questions such as, "what was that like for you?" and "can you elaborate on that?", as well as going with the nature of the conversation to discuss topics that were brought up during the sharing of information. The open-ended questions asked and the informal format of the interviews allowed for participants to express themselves freely and share their stories, thus more qualitative information was collected (Alsaawi, 2014).

Prior to starting the interviews, I advised the participants that the interview would be audio recorded through a transcribing application on my phone, 'Otter AI', and that this application would help me keep note of all important information mentioned in the interview and would allow me to look back on the interview itself. I also informed the participants that only I will hear and read the transcriptions. Before starting, I advised participants that they were able to request to stop the recording at any point and they may skip a question if they were uncomfortable in answering. The common topics I asked the participants were about their diagnosis journey and how they came about getting a clinical diagnosis, the symptoms they have and/or are currently experiencing, any

endometriosis treatment, surgical or medical history, and their current views on their health and endometriosis journey.

### *Journals and Pain Scales*

At this initial interview I also showed the participants their journals, explaining that they were to write in them every day for 12 weeks and answer the daily pain scale (Appendix H). For the first four weeks, they only answered the pain scales and wrote in the journals, and no yoga was implemented. Yoga classes were implemented on the fourth week, starting the 24<sup>th</sup> of July, for the next eight weeks. Additionally, during the days they had yoga, participants were to answer the pain scale before and after the yoga sessions (Appendix H). The pain scale implemented in the journals was the NRS ('0- no pain at all' to '10- worst possible pain'), as it is one of the most commonly used and valid scales assessing endometriosis pain (e.g., dysmenorrhea, CPP) (Fauconnier et al., 2018), reliable (Tavares de Arruda et al., 2022), quick, and simple to use for daily pain assessment (Bourdel et al., 2015). I stated that they had the freedom to write down any other information they wish (e.g., menstruation pattern, elaborating their pain, describe other symptoms, etc), and that this was encouraged. The endometriosis health questionnaires were also shown and given to the participants, clarifying that they have to complete one 25-question survey on the first and last day of the research, as well as complete a shortened (5 questions) version which was stuck onto their journal, 6 weeks into the research (Appendix I). The format and content of the endometriosis questionnaires were influenced by that of the EHP-30, consisting of 25 questions across domains from the EHP-30 core and supplementary segments (pain, control and powerlessness, emotional wellbeing, self-image, sexual relationship). The shortened version comprised of 5 questions covering the same domains (pain, control and powerlessness, emotional wellbeing, self-image, sexual relationship). I explained that if participants were unable to attend a yoga class for any reason (e.g., in pain, work, emergencies, etc), they should make note of this in their journal, contact me and I would then inform the yoga instructor as well. The interviews ranged from 28 minutes to 73 minutes, averaging around 48 minutes. Finishing the interview, I then went over the consent form with the participants, and clarifying any questions they may have had.

### *Yoga Sessions*

The yoga sessions were held at the Milford Senior Citizens Club on Mondays and Fridays from 1:30pm-2:30pm. The first yoga class started on Monday 24<sup>th</sup> of July and the last yoga class was held on Friday 15<sup>th</sup> September. A total of 16 yoga classes were held. If any participants were unable to attend the yoga class, they were advised prior to starting the research that they should

inform myself so that I may then inform the yoga instructor. The structure of the yoga classes varied class-to-class in that the poses, breathing and relaxation exercises taught by the instructor depended on the needs of the participants that day. For example, the yoga instructor would ask the participants at the start of the class if anyone had any parts of the body they would like to be focused on and for example if a participant/s expressed that they were feeling more pain on their back, the instructor would incorporate poses and exercises that targeted the back that day. The yoga instructor would also ask the participants before the class ended if they had any suggestions as to what they should focus on for the next class. If no suggestions were made by the participants, the yoga instructor would decide what areas of the body or exercises to focus on for the next class based on their observations of the participants that day (e.g., if yoga instructor observed that participants had difficulty in upholding posture, the next class may have some focus on postural exercises. The focus of the yoga classes are detailed in Table 2.

**Table 2**

*Focus of yoga sessions*

Week	Focus	
	Monday	Friday
1	Full body	Shoulders and lower back
2	Strengthening and legs	Lower body (strengthening and stretching)
3	Full body	Balance training and lower back
4	Full body (dynamic poses)	Lower body and shoulders
5	Full body	Lower body
6	Balance and core training	Full body
7	Balance and core training	Lower body
8	Full body	Full body & some partner posing exercises

After the first week of yoga classes, the yoga instructor, Samantha, had inquired whether it was possible for her to take photos of the yoga sessions, making sure the participants' faces were not captured. She stated that this would help the participants see and compare their progress throughout the programme. I advised that as this was outside of what was planned for the research, this needed to be brought up to the participants themselves and that she would need to obtain their permission before taking their pictures. In the next yoga session, Samantha asked the participants

## ENDOMETRIOSIS & YOGA

regarding this and all four of them gave their consent for her to take their pictures. She did not post any photos onto her social media, instead the photos were shared with the participants after each class so that they were able to track their progress and improvements over the yoga sessions by looking at their pictures.

### *Second Interviews*

The second interviews were coordinated with the aim to get an understanding of each participant's personal experience with the research and how yoga impacted their pain caused by endometriosis. The final yoga class was on 15<sup>th</sup> of September. Second interviews were then held with the remaining participants (Miriam, Tessa and Margaret). Interviews were held with each participant individually at a location decided by the participants. Two interviews were held in the participants' homes and one interview was held at a meeting room in the AUT library. The structure of the interviews was semi-structured and conversational in nature. I created a rough guideline consisting of questions to ask the participants and topics to raise, such as enquiring about the participants' individual experiences with the yoga, journal writing and research itself (Appendix G), however, the flow of the discussions was led by the nature of the conversations. Prior to starting the interviews, I reminded the participants that the interviews would be audio recorded using the 'Otter AI' application on my phone.

Common questions I asked the participants were related to the topics of the social aspect of the yoga class, and how they felt the yoga impacted their pain levels, mental and physical health, and emotional wellbeing. I also asked about their experience in writing in a journal every day for reflection. This allowed the participants to tell me themselves what factors they thought helped or hindered the efficacy of yoga as a pain management for their endometriosis pain and symptoms, showing their subjective standpoint of their experience. Lastly, I reminded the participants that they will be sent transcripts of both interviews (first and second) and that they have two weeks to approve or make changes. A non-response was considered an approval from the participant.

### **Challenges**

There were many challenges for this research. Firstly, prior to the research starting, selecting a yoga instructor and organising the time, days and location for the yoga classes was challenging. The yoga instructor was advertised to be paid \$30 per hour/session but this was a lower rate than what qualified yoga instructors are paid on average (typically \$45 an hour) (PayScale, 2023). This decreased my chances of receiving a great amount of interest. I was also looking for a yoga

## ENDOMETRIOSIS & YOGA

instructor who was genuinely passionate in yoga and helping women with endometriosis, and who believed in the research ethos, rather than one who was driven by monetary motivation.

The second challenge was with organising the days, time and location of the yoga sessions. This involved talking to a number of potential locations. One place initially provided me with information which suited the financial budget for the research and they were prepared to organise the yoga sessions commencing in July. Unfortunately, as time got closer to the recruitment and selection of participants and the staff finally admitted that they were yet to coordinate days for the yoga sessions. This delayed the process in selecting participants during the screening process, as I was unable to inform them of the days, time and location of the yoga classes. As well as delaying participant recruitment, it reduced the efficiency of the selection process.

The third challenge was retaining my participants. Two weeks into the research, one participant, Holly, had advised that she had been scheduled for a surgery, meaning that she would not be able to join the yoga sessions and therefore would need to withdraw prior to its commencement. Holly participant wrote in her journal for four weeks and completed the pain scales until this date. Another participant, Sarah, contacted me six weeks into the research and informed that she would like to withdraw. She had not attended any yoga classes (four classes had occurred by this time) as she had been sick with the flu and this caused her to have a very bad flare up of her endometriosis. She had written in her journal and completed the daily pain scales. Both Holly and Sarah were happy for me to include their data in the research and had given their consents. The only information I could analyse was their history recollection and personal accounts of endometriosis. However, the recollection of their endometriosis journeys was nevertheless very valuable as it gave plenty of insight as to how women can live with endometriosis and the pain associated to the illness.

Furthermore, 10 weeks into the research and six weeks into the yoga classes, one participant, Margaret, presented me with another challenge. She announced that she would no longer be able to attend the yoga classes due to increased work responsibilities. It was decided that I would record the forthcoming yoga sessions and email each of them to the Margaret until the end of the programme. The yoga sessions were recorded from the 1<sup>st</sup> of September until the 15<sup>th</sup> of September using my mobile phone. Each class was recorded and emailed to her on the same day (e.g., I would record a Friday yoga class and at the end of the session, I would email the recording to the Margaret). This was not ideal because watching a recording, she did not have the guidance of a yoga instructor to correct or adjust their postures and poses. Another reason why giving Margaret a recording of the yoga class was not ideal, was because this reduced uniformity in how, when and

where she would practice yoga as the social aspect is also a factor to be considered. Attending the yoga classes in-person, participants were able to interact with the instructor, myself and each other, and practicing yoga in a space with other people may also come with different motivational inclinations compared to practicing a recorded yoga class at home alone.

Another challenge to the research that happened quite frequently was the absence of participants in the yoga sessions. My supervisor and I did anticipate that participant retention might be an issue, hence a more qualitative exploratory approach to the research design rather than a quantitative exploration of yoga effectiveness on pain management. Also, even the fact that participants were unable to attend due to pain reflects the reality for many women with endometriosis and their desire to try strategies that may help them. Despite all the challenges, I still have a wide range of different types of data (pain scales, journal reflections, and interview data).

### **Analysis**

Throughout the research, participants had many opportunities to their endometriosis journeys, their experience with endometriosis-associated pain, and its impacts on their lives and the impact of yoga. They were able to share this during the interview phases (initial and closing interviews) and through writing in their journals. During the analysis process, I evaluated the contents of each participant's initial and closing interviews, their daily pain scale answers, and their journal entries. In this process, I observed that whilst no two participants' experiences were identical, they all shared similarities in the experiences they endured in living with endometriosis. Acknowledging these shared similarities and conducting an RTA guided me to constitute themes and subthemes which illustrated the participants' subjective lived experiences (Braun & Clarke, 2013) with endometriosis and pain, and their impacts on various domains in their lives.

### ***Scoring of Endometriosis Questionnaires***

The Endometriosis Health Profile (EHP) is a disease-specific questionnaire that measures the impact of endometriosis on HRQOL (Hansen et al., 2021). The long-form core questionnaire (EHP-30) consists of 30 questions across five scales which have been deemed important to women to their QOL: pain (11 items), control and powerlessness (6 items), emotional wellbeing (6 items), social support (4 items) and self-image (3 items), whereas the short-form (EHP-5) consists of one item from each of these five scales (Oxford University Innovation, 2016). The questions are asked in regards to the patients' experiences with endometriosis within the last four weeks and are answered using a 5-point Likert scale where 0=never, 1=rarely, 2=sometimes, 3=often, and 4=always (Taylor et al., 2020). Additionally, there are six modular scales comprising of 23

questions which are optional to use alongside the core five scales. These six supplementary scales are: work (5 items), relationship with child/children (2 items), sexual relationship (5 items), feelings towards medical profession (4 items), feelings about treatment (3 items), and feelings towards infertility (4 items) (Oxford University Innovation, 2016). The endometriosis questionnaires I implemented in my research were influenced by the design and content of the EHP.

I gave participants the same endometriosis questionnaire to complete on the first day of the research (24<sup>th</sup> of June) and on completion of the research (15<sup>th</sup> September). This questionnaire comprised of 25 questions related to both the core and supplementary domains of the EHP: pain (10 items), control and powerlessness (5 items), emotional wellbeing (5 items), self-image (3 items), and sexual relationship (2 items). A short form of this questionnaire was also made and attached to the participants' journals. The short version comprised of 5 questions, one item from each domain covered in the long-form. This shortened questionnaire was completed by participants midway through the research (6 weeks into the research), two weeks since the implementation of yoga. Participants were asked to reflect on their experience with endometriosis and pain over the last four weeks when answering both the long and short questionnaires. They answered using a 5-point Likert scale where 0=never, 1=rarely, 2=sometimes, 3=often, and 4=always, producing quantitative data, the same format as the EHP. Having the same format as the EHP, the participants' questionnaires in my research were scored the same way; maximum possible raw scores for each domain were first determined. Then raw scores (sum of items in each domain) for each domain were divided by the maximum possible raw score and multiplied by 100 (Bourdel et al., 2019). The scores ranged from 0 to 100, where 0= best possible HRQOL and 100= worst possible HRQOL (Hansen et al., 2021; Taylor et al., 2020). I then created a small line graph for each participant consisting of their scores on each domain of the endometriosis questionnaire from the start of the research, midway through the research, and at the end of the research.

### ***Pain Graphs***

Besides the EHP scores, another quantitative aspect of the research which produced numerical data was the graphs of participants' pain levels. Each participant's daily NRS pain scores were collected analysed, and their mean and median pain levels were calculated for each week. Next, line graphs were created to illustrate the mean and median NRS pain levels for each participant across the weeks they were involved in the research. Line graphs were used because this style of graph was able to best capture the changes in the participants' mean and median pain scores across the time frame of the research, as well as show the overall trend for each participant's pain levels as they go through the research and practice yoga (Better Evaluation, 2022). The yoga was

implemented from week six through to week 12, and the classes were held on Mondays and Fridays. In the participants' journals, on the days they had yoga, there would be two pain scales for them to complete. They were to complete one pain scale before yoga, and the other pain scale after yoga. Completing two pain scales in one day meant that this affected the total amount of data collected, as well as impacting the analysis of their mean and median scores. Up until week five, the mean and median pain scores were analysed normally. Starting from week six, on the days the participants had yoga (Monday and Friday), I took the average pain score for those days and used that score when trying to find the mean and median pain levels for the week. For example, if on Monday a participant scored a level 6 pain before yoga and scored a level 4 pain after yoga, the average for that day was 5. The score of 5 would then be the pain level for that Monday, and along with all other pain scores for the week, the scores were summed and divided to then find the mean pain level for the week. To find the median, the same rules applied in that I found the average pain level on the yoga days. Those numbers then became the pain score for that day, and became part of the data set of pain scores for the week in which I analysed to find the median. Participants Holly and Sarah withdrew from the research without attending any yoga classes and so they did not complete any of the 'before and after yoga' pain scales.

### ***Reflexive Thematic Analysis***

Carrying out the thematic analysis for my research, I followed the step-by-step guideline developed by Braun & Clarke (2006), outlining the six phases of a thematic analysis.

***Phase (1): Familiarising the Data.*** This involved reading and listening to the data over and over again and transcribing the participant interviews and journal entries, immersing myself in the data and searching for meanings and patterns. Listening to the transcriptions, I noted the tones, breaks, and pauses used by the participants (Braun & Clarke, 2013). I listened to each participant's interviews once without making any notes and recalled on their tones and mannerisms they used during the interviews. Listening to them again, I then downloaded the transcriptions of the interviews from the 'Otter AI' application to my laptop, read them and then edited them to ensure there were no overlaps of speakers in the transcriptions. I then started to make notes of any trends I saw or recurring themes, as well as noting down my thoughts on the data.

***Phase (2) Coming Up With Codes.*** This involved coding the data and categorising each participant's data set to relevant codes. Both semantic and latent coding was used. Semantic coding is simply describing the data at face-value, whereby latent coding guided me to analyse underlying assumptions and ideologies, trying to find possible hidden meanings to the presented data, taking on

a more interpretative and active role as a researcher (Byrne, 2022). Codes were noted in the side margin of the 'comments' section in Microsoft Word.

***Phase (3) I Searched for Themes.*** I collated each participant's data set to themes and subthemes. I colour-coded the themes and subthemes and highlighted excerpts in the participants' transcripts and journal entries with the matching colours to the themes and subthemes. As I was understanding each participant's history with endometriosis at this phase, I found that they all shared a similarity in tolerating the pain and living with what they thought were "normal" period symptoms. Lead by a specific event and through self-research, participants sought information and medical advice. Seeking for answers, this initiated their battle for diagnosis and participants commonly described feelings of frustration, anxiety and relief in their stories. As the interview transcripts were the first data set that I analysed, Themes One and Two were found first. Finding Theme One and Two and their subsequent subthemes was not a linear process, as they were found not only through the analysis of the transcripts of the initial interviews, but also through analysing the participants' journal entries, endometriosis questionnaires, and their closing interviews, going back and forth through each data set and adding on more subthemes as they are found. I then created a table for each participant which included the colour-coded themes and subthemes and categorised the excerpts from their interviews and journal entries into them. Again, during this analysis, the process in developing themes and subsequent subthemes was not linear; I went back-and-forth through each participant's journal, noting down their answers and scores to the endometriosis questionnaires and daily pain scales, reflecting upon the data to code and find themes related to my research question. Unlike analysing the transcripts of the initial interviews though, I felt that reviewing the participants' journals required me to reflect and decipher the data set more. This was because the participants treated the journals as their own private diaries (as they were told to), rather than to try and write like they were speaking to me, such as in an interview, where they would answer specific questions I asked them. So, some of the themes and subthemes found throughout the analysis of the participants' journals were developed through my personal interpretation of the participants' responses, embracing reflexivity in RTA (Braun et al., 2022).

***Phase (4) Evaluated Themes.*** I reviewed the themes subthemes and checked to see whether they worked in relation to the codes I identified, as well as the entire data set. This was a time where I spent time looking within and across the participants data to refine and look at the experiences as a whole. I also started to look at the questionnaires and quantitative data alongside the themes to explore the participants pain across the study.

***Phase (5) Named and Defined Themes.*** I analysed and specified each theme and subtheme, making sure they each had clear definitions. This was very much an iterative process of writing, thinking, reflecting and repeating this process.

***Phase (6) Produced the Report.*** I selected extracts across the participants' interviews and journal entries as examples in how they related to the research question of the impacts of yoga on endometriosis pain, QOL and other domains within the participants' lives (Braun & Clarke, 2006). I was considerate in making sure I included suitable quotes and key-points shared by participants in their interviews and journals to support and emphasise the themes I believe they were trying to convey. Being contemplative as a researcher was key as I had both qualitative and quantitative data and deciding on what to include in the write up involved reflexivity and many discussions with my supervisor.

### **Chapter Four: Findings**

This chapter will detail the main findings of this research on yoga as a method of pain management for endometriosis. A summary of all of the themes and subsequent subthemes found within the dataset (Appendix J) will be discussed in this chapter. The findings also include the participants' scores on each domain of the questionnaire, as well as any changes in their scores over the course of the research, and what this means. I include graphs of the participants' pre-test, mid-test and post-test endometriosis pain scores. Furthermore, this chapter will also outline each participant's experience with pain, depicting the changes in their perceived pain levels across the time span of the research.

#### **Overview of Themes and Subthemes**

I began with the analysis of the initial interviews where participants shared their endometriosis journeys, their paths to diagnosis, impacts of pain and other symptoms on their lives, and experience with miscellaneous medications and treatments. This led to Theme One and Two (One: Experiencing Endometriosis Pain; Two: Treating Endometriosis Pain). Theme One relates to the physical pain that the participants experience in living with endometriosis. This subject of physical pain is a broad topic. Theme Two covers the various treatment options for the participants, including treatments they had previously tried, treatments they were currently taking, and the lack of options they were presented with. Such medical and non-medical treatments were taken and tried by the participants due to various reasons such as simply being prescribed by doctors or due to having a lack of treatment options due to disbelief and disregard of their endometriosis symptoms.

The next data set that was analysed was the participants' journals. This included their journal entries, endometriosis questionnaires (pre-test, mid-test and post-test), and the scores to their daily pain scales. The following themes were found during the analysis of the participants' journals and its contents alongside the two interviews: Theme Three: Yoga and Quality of Life (QOL), Theme Four: Benefits of Yoga on the Body, Theme Five: Benefits of Yoga on Mental health, Theme Six: Yoga and Perception of Pain. Themes and subthemes that were found are detailed in Table 3.

**Table 3**

*Themes and subthemes related to the effectiveness of yoga as pain management for endometriosis.*

Themes	Subthemes
Experiencing endometriosis pain	Pain and diagnosis journey Control and powerlessness Intersection of mental and physical wellbeing Pain and quality of life (QOL)
Treating endometriosis pain	Medical options Lack of options Self-management
Yoga and QOL	Mental wellbeing Self-image Social support
Benefits of yoga on body	Flexibility Muscle toning Stretching Challenging Short-term pain relief
Benefits of yoga on mental health	Confidence Control Independence
Yoga and perception of pain	Participants' reflections on their yoga experience and endo Effect on perceptions of endo-associated pain

**Theme One: Experiencing Endometriosis Pain**

As participants described their endometriosis journeys, they commonly shared their stories of hardship in living with the disease and specifically, how pain was the root of such hardship. The symptom and experience of pain initiated the start of many of the participants' long road to diagnosis and ongoing struggle of grappling with the illness. The participants spoke about their pain in many ways and how it affected their physical and mental wellbeing.

### *Pain and Diagnosis Journey*

Throughout the research, the focus was around the participants' subjective experiences of endometriosis-associated pain. Interestingly, the participants all shared something in common, which was that pain was what caused them to start searching for medical advice and seeking for answers; and ultimately a diagnosis to explain (and validate) what they were experiencing. In New Zealand, the usual process of getting an official diagnosis for endometriosis is for patients to go to their primary health care (GP) whereby the GP then evaluates the patient's presenting symptoms and determines whether further examination is required to make a diagnosis and provide treatment (Ministry of Health, 2020). Unfortunately, it is not uncommon for women with endometriosis to experience feeling that their pain and symptoms have been dismissed by doctors (Ellis et al., 2023), and this was seen to be a shared experience across four out of the five participants in the research.

Participants had experienced doctors minimising their pain and other symptoms, as well as being told that they were presenting menstrual symptoms. One participant, Sarah, described how the many specialists she had seen had told her that her symptoms were "*normal*" and dismissed any possibility of her having endometriosis: "...*he (gynaecologist) did an internal exam and he was like, "oh your cervix is so malleable. I would highly doubt that you have any endometriosis"*". On one side, it can be argued that primary health care doctors such as GPs may be more reluctant to diagnose a patient with endometriosis as they may not be as knowledgeable and do not have the same level of expertise as more qualified specialists (Grundström et al., 2016). Contrastingly, this does not explain why GPs would then show reluctance to refer the patient to a gynaecologist, nor why some specialists also still dismiss patients' symptoms and experiences, showing reluctance to diagnose.

The participants described doctors having dismissive attitudes towards their symptoms and their experience, and this was perceived as misogynistic. One participant, Margaret, detailed how a doctor undermined her pain tolerance: "...*she did the whole like, "oh look, maybe your pain tolerance is really low"*". This was construed by the participant to be a condescending and sexist statement from the doctor, as she believed that if she was a male, the doctor would not have accused her of having a low pain tolerance. Another participant, Miriam, also insinuated how doctors can and have shown to be sexist through their dismissive attitudes. She stated, "*I've had a lot of health problems before, not related to my ovaries and my reproductive area...and it's so funny the difference of how doctors treat you and how the whole medical field looks at it when it's a woman's reproductive area versus not...it's like an inconvenience...they just brush it off.*"

The dismissal of symptoms and reluctance to diagnose has no doubt played a major role in the delay of diagnosing endometriosis (Ellis et al., 2023). Within the participant group, it took them 3, 7, 8, 12 and 21 years to get diagnosed from the time of symptom onset, which is an average of 10.2 years. Waiting long years to get diagnosed has caused adverse effects on the participants' mental health, causing anxiety, stress and self-doubt. Sarah explains, "*...there's nothing worse than being told it's all in your head...when you know that there's something fundamentally wrong with your body...the length of time it took to get to that diagnosis without a doubt has contributed to my mental health struggles over the years for sure*". Having experienced dismissive and belittling attitudes from doctors, the majority of the participants have formed distrust in the New Zealand health care system and in medical professionals, believing that patriarchal ideology and misogynistic sociohistorical constructs of women have indoctrinated even the medical realm, creating serious problems in their diagnosis and overall journey of endometriosis.

### ***Control and Powerlessness***

All of the participants in the research mentioned that endometriosis had control over their lives to some degree. This sense of powerlessness stems from a combination of a lack of effective treatments, leading the participants to feel unable to control their pain. This then affects how they go about their day-to-day lives, as well as influencing their overall functioning and decision-making on more serious matters in their lives (Van Stein et al., 2023). Feeling like they were powerless in controlling their illness and pain was a common thread amongst the participants. They feel the need to shape their life to accommodate their pain and endometriosis, as opposed to trying to manage their endometriosis to suit their lifestyle. As they are unable to do the latter - due to there not being definitive effective treatments – they are overcome with feeling powerless. Words such as "*tolerating*", "*dealt with*", and "*lived with*" clearly suggest that the participants are withstanding the pain because they simply have to in order to keep going with their lives because they have no other choice. Participants portrayed their helplessness in such examples: "*nobody wants to be popping pills for the rest of their life*", "*I don't want this to have to dictate my personal choices*", and "*you feel hopeless or helpless*".

Margaret was the only participant who shared how endometriosis affected her fertility and she was the only participant who was trying to start a family at the time of the research. She expressed that being 35 years old and having stage four endometriosis, she was prioritising starting a family. One way Margaret felt she could help with this was to refuse hormonal medication suggested by her doctor:

*“So, we’ve decided to go that route because I think **I just feel like I want to be in control of something**<sup>4</sup>...and if I go on the pill and am waiting for surgery, I don’t know when it’s gonna happen. I know I can’t get pregnant because I’m on the pill. **So, what do I have control over?** Whereas this route, although I know I’m gonna probably be in more pain because I’m not on the pill...we know we want to start a family, so at least that’s something I can go after.”*

By avoiding contraceptives and sacrificing feeling pain in order to be able to start conceiving, Margaret is putting matters into her own hands by deciding what she has control over. In this case, she has decided to be in control of her family planning and not let endometriosis and the pain take over her life. With endometriosis affecting many aspects of her life, Margaret chose to stop the pain controlling at least one aspect which was most important to her, her fertility.

### ***Intersection of Mental and Physical Wellbeing***

From undergoing the diagnosis journey to bearing the pain and other symptoms for most of their lives, to live with endometriosis is to fight a mental battle. Although pain and endometriosis are physiological phenomena (Srnđu, 2022), their effects on the individual extend outside of just physiology, impacting also their mental and emotional wellbeing (Gonzalez-Echevarria et al., 2019). It was a common thread that they encountered dismissive attitudes towards their pain and symptoms from many different people. For example, one participant, Holly, recalled her gynaecologist being reluctant to accept Holly as having endometriosis and not providing her with medical advice or treatment:

*“I kind of got to the point where like, even though I was having periods like every single day, and my gynaecologist was still like, “I don’t think it’s a gyny problem” ... I’ve been through every other path. And she like, diagnosed me with it (endometriosis). And then she was like, because she couldn’t help me or like, figure out what to do, **she basically just shoved me off**. So, I’m waiting for a second opinion.”*

Holly had experienced frustration and confusion: “...she’s like, “oh it must be your diet”. And I’m like...I’m confused”. Being essentially disregarded by her gynaecologist who is supposed to be a specialist in endometriosis and a medical professional who provides aid and treatment, not getting any answers and being disregarded by her doctor left Holly feeling frustrated towards her doctor for being attentive towards her health. Years and years of experiencing frustration due to dismissal by

---

<sup>4</sup> The bold text is my emphasis.

doctors and not getting appropriate help can cause negative mental strain on the individual, stop them from continuing to seek medical advice and treatment, and also cause self-doubt.

Another participant, Sarah, experienced her mental health take a toll as she was going through the long diagnosis process. She explained:

*“It was pretty horrific. And essentially, there’s nothing worse than being told **it’s all in your head**...when you know that there’s something fundamentally wrong with your body and **people just keep telling you that you’re making it up**, that you’re a hypochondriac... that this is not what it is.”*

After getting dismissed by numerous specialists and being told again and again that it was all in her head, Sarah started to question herself and her sanity, and was full of self-doubt. She expressed: *“...so with that whole process, I was kind of getting to my wit’s end because I was actually feeling insane”*. These are only two examples illustrating a clear intersection between mental and physical wellbeing and how the two concepts cannot be separated from one another when trying to understand endometriosis pain and its effects. Other impacts of pain on mental health mentioned by the participants include guilt, anxiety, fear, stress, mental and physical fatigue, and sleep quality (Appendix J).

### ***Pain and Quality of Life***

The participants’ social life seemed to be affected in one way or another by the pain associated with endometriosis, such as through feeling a lack of social support. Lack of social support was shared by Tessa, Miriam and Sarah. Tessa also felt that her mother had put some blame on her for having endometriosis: *“it kind of sounds like she is blaming me because I’m not looking after myself.”* Feeling this blame put on by others can also have adverse effects on emotional wellbeing and self-image. For example, after explaining how her mother blames her for having endometriosis, Tessa started questioning whether she really was lacking in self-care and thus thought negatively of herself: *“then it becomes another issue for me, like “oh am I really not looking good after myself?”.”*

A few of the participants also mentioned that pain and other endometriosis symptoms had added extra challenges to dating. Sarah described how the topic of having children was brought up by her doctor during a medical consult and so she was confronted with having to discuss the topic with someone she was newly dating. This situation highlights how endometriosis can affect both individuals in the relationship (Van Stein et al., 2023). Having endometriosis can make women and their partners more quickly discuss and seriously consider their time frame for starting a family and

## ENDOMETRIOSIS & YOGA

if this is even what they want. They can be faced with the pressure of having to confront this topic with partners earlier on in the relationship: *“I was sitting with the guy that I’d been dating for like, maybe six months, and the doctor’s like, “have you thought about having kids?” and I’m like, I looked at him and like, “well, no”. And he’s like, “maybe you should consider it”. I’m like, ugh!”* Furthermore, participants had also mentioned the effects of pain and endometriosis on self-intimacy and intimacy with a partner: *“it also really impacts your dating life...when you’re a fucking literal bleeder, like, sexy. It really fucks your whole life up.”* The impact on intimacy and sexuality was also shown through the participants’ scores on the endometriosis questionnaires. Fertility is another domain that commonly impacts endometriotic women and one that was affected for one participant in particular, Margaret. She was the only participant that was actively trying to conceive and described that despite all the fertility testing she and her husband had done, her endometriosis was the only preventing factor: *“...the endometriosis is still blocking that.”*

Another social domain, employment, was one that the participants expressed had been affected by their endometriosis. Holly described her employment situation:

*“I’m not working...So I **had to leave my job**. So, like, the last two jobs that I’ve had, I’ve had to leave after between like half a year and a year and then I’ve had a year off working after both jobs because I kind of just...you know... **go through the waves** (pain) and it’s like really bad and then it’s fine and it’s really bad. And... yeah, but I’m currently trying to find like a job that’s more **accommodating**. Just doing like a day a week.”*

Having to find a job that is accommodating was also a common thread found with Miriam. Her decision to be self-employed was highly influenced by her pain and endometriosis and her effort to accommodate the pain: *“...that was a decision I made like really soon after noticing the pain. It was really important to me that I’d had like my own work schedule and that I would just be able to like yeah, just work when I was actually able to.”* The social support from place of employment was emphasized by Margaret, as she explained how fortunate she felt having understanding employers: *“because if there are those days where you have a flare up and your boss isn’t understanding, it can be an issue”.*

### **Conclusion**

Overall, Theme One showed how pain is an overbearing burden, affecting every aspect of their lives. Pain also had power to shape negative life-changing repercussions. There was particular emphasis on how pain affected mental and physical well-being and quality of life. This is important to keep in mind when exploring yoga and its impact.

### **Theme Two: Treating Endometriosis Pain**

The treatment of endometriosis pain varied across participants from prescribed medication to over-the-counter options and self-management methods. The lack of treatment options was also a subject matter that all of the participants expressed concern on, highlighting the evident issue that has long been circling endometriosis. Furthermore, three out of the five participants had also undergone laparoscopic surgical treatment for their endometriosis and so this was discussed in the individual interviews. In exploring the topic of endometriosis treatments, the participants did not shy away from sharing their feelings towards the medication they had been prescribed and their effectiveness in actually treating their pain and endometriosis.

#### ***Medical Options***

All of the participants expressed that their doctors would discuss and suggest hormonal medication. This came in the form of the Mirena and oral contraceptives. When participants spoke of how their doctors suggested them to take hormonal medication, the participants commonly shared feeling some hesitancy in putting extra hormones in their body: “...it’s just like, one more thing that I’m introducing to my body and I...am hesitant about that” and “and then I think the other side effects...it’s about my emotions”. The suggestion of hormonal medication as frontline treatment from doctors may have been due, to some extent, to the fact that this is what the Ministry of Health states in their guideline (2020). Nevertheless, the effectiveness in using the Mirena and oral contraceptives varied largely amongst participants, highlighting the subjectivity in experience of pain and endometriosis symptoms and potentially highlighting the ineffectiveness of hormonal medication for pain. The Mirena had a positive impact on controlling Miriam’s periods and reduced the heavy flow of Sarah’s periods, however it was only temporarily effective for Holly, as it eventually worsened her symptoms and caused her to bleed constantly for one whole year.

Medication for nerve restoration was also prescribed to Miriam. Due to being in constant pain over a number of years, Miriam’s nerves were substantially damaged and were therefore more sensitised, requiring them to be restored through taking amitriptyline temporarily. Miriam had noticed a decrease in pain intensity whilst she was on amitriptyline. This medication was not a permanent solution to her pain or treatment of endometriosis. Additionally, whilst most of the participants would consume over-the-counter painkillers such as Panadol, Holly was the only participant who was prescribed Tramadol and Venlafaxine for pain relief. This did not help with the pain and so she was stopping her consumption. Nevertheless, she expressed that she still takes Panadol and Tramadol to help ease the pain, even if only for temporary relief.

Lastly, laparoscopic surgery is supposedly thought of as a more prominent treatment for endometriosis (Foster & Leonardi, 2021). Three out of the five participants had undergone laparoscopic surgery for their endometriosis, with Holly having undergone laparoscopy twice. Despite having gotten surgical treatment more than once, Holly claimed that it has not helped, and when asked about whether she thought the laparoscopies had helped with her pain, she claimed, “...*not at all. Probably gotten worse*”. Sarah also seemed to think that her laparoscopy was only a temporary treatment, as since years had gone by since her surgery, she believes that her endometriosis is coming back. She said: “*100% my symptoms are coming back and I’ve actually noticed that my health is getting a lot worse.*”

### ***Lack of Options***

The participants also discussed a lack of viable options for their pain and symptoms. This lack of options often stemmed from the disbelief by doctors of the participant’s pain and minimising their pain to ‘normal’ menstrual pain. By dismissing and not giving a diagnosis for the participant’s condition, the doctors would then also be reluctant in prescribing treatment or medication. Doctors who showed disbelief in the participant’s symptoms would also be reluctant in referring them to specialists for further examination, such as getting an ultrasound or MRI. For example, Miriam explained how she was a virgin before marriage and was a virgin during the time she was trying to get diagnosed for endometriosis. She described doctors refusing to conduct pelvic examinations and internal scans on her because of this decision:

*“So, like, I was like, “you know, I haven’t had anything up there, so, like, it’s really painful when you guys...” and I didn’t know if that was the norm or not because I had never had sex. So, I didn’t know. And then you know, **they would like, refuse to do like, internal scans on me...Like they would say, “no, since you’re a virgin, we don’t want to do that”.** And I was like, but I want to, like I don’t care, like, it’s medical.”*

Being dismissed not only delayed her diagnosis, but because of this delay, Miriam was also unable to receive treatment and endometriosis-specific medication earlier. Participants had recalled doctors insinuating that they were dramatizing their symptoms and in Tessa’s case, the severity of her endometriosis. Tessa claimed that her doctor did not show apprehension at her endometriosis: “*so she said it’s not that serious*”. Other participants described how having a low pain tolerance was what made them heighten the pain, according to doctors. Margaret stated, “*I then saw a doctor who basically made me feel like I was making it up... she did the whole, “well look, maybe your pain tolerance is really low”.*”

Besides endometriosis, participants recalled doctors previously diverting the cause of their symptoms to be of other origins and indications of other illnesses. Holly exclaimed that her specialist who had diagnosed her with endometriosis would imply that her constant bleeding and pain was due to her diet: “...every time that I have like, really bad pain, I get bleeding with it. And so, she’s like, “oh it must be your diet”.” Again, this redirection of symptoms onto other conditions besides endometriosis is slowing down the diagnosis process which in turn affects the rate in which patients can receive treatment. Depression and stress have also been suggested by doctors as the cause for the participants’ symptoms. Sarah explained:

*“I saw a gynaecologist in 2020. And I went in to see this woman and I was telling her about my symptoms and she says, “oh **I think it’s emotional trauma from your brother’s demise. It’s got nothing to do with endometriosis**”. I shit you not. She wrote that in the notes and sent it to my GP. I remember sitting there thinking, “so you’re telling me, my brother’s death...**completely dismissing my physical feelings** and the fact that I’ve seen other gynaecologists before you?”.”*

Again, this was an experience shared by Sarah of how a specialist was so quick to dismiss her physiological health and instead suggest that the physical symptoms were due to mental struggles. This showed not only how women with endometriosis can come to see a lack of treatment options due to dismissal in diagnosis, but also by the doctor attributing the physical symptoms as result of psychological strain. This points to the intertwining of the physical and psychological in endometriosis and health but also the complexities of this.

### ***Self-Management***

It was interesting to see the diversity and range of self-management methods that the participants used to help ease their pain. One of the most common methods used by the participants to help alleviate the pain was a hot water bottle. Three out of the five participants recorded using this in their journals and would use the hot water bottle frequently. Jo and Lee (2018) found that using heat is a common method for relieving menstrual cramps and that heat can help relax muscle tension. Participants Tessa and Miriam also made changes to their diet to try and mitigate their endometriosis and pain from the inside. Tessa expressed that she follows the values of Chinese medicine. Within the teachings of Chinese medicine, it is thought that too much consumption of ‘cold’ foods is detrimental to blood circulation, precipitating inflammatory properties in the body to accumulate and cause aggravate muscle tension and pain (Teng, 2023). Therefore, Tessa explained that she had been trying to cut out cold foods such as dairy products and raw food. On the contrary,

## ENDOMETRIOSIS & YOGA

Miriam has incorporated anti-inflammatory foods into her diet since 2022. She now only uses avocado oil for cooking, consumes less red meat and eats more raw food. Since incorporating an anti-inflammatory diet into her lifestyle, Miriam has noticed a slight improvement in her pain and hormonal breakouts.

Participants also practiced relaxation and breathwork when they were in pain. For example, Miriam mentioned in her journal entry that she “*was able to take a nap which helped manage the pain a bit*”. Resting her body to ease the pain gave some indication that perhaps her body was fatigued and taking a toll from being in constant pain that it just needed to rest (a break). Margaret on the other hand had described during her closing interview that she had implemented more breathwork since the research started. She was unsure as to whether she subconsciously started this because of the research and yoga or not, but she found that the breathwork exercises did help her to feel calmer and more relaxed when nervous and stressed (i.e., when in pain). Furthermore, light physical activity such as stretching and yoga were also implemented by some of the participants to help reduce pain. A few of the participants had previously done some yoga prior to the research and have said that they found it beneficial to both physical and mental health: “*it was really, really good for my mental health*”. Since doing yoga in the research, two out of the three participants left in the research at this time would practice yoga in their own time. Tessa said that she would sometimes do the frog pose after work to relax and work on her pelvic flexibility. She stated that doing the frog pose helped relax her lower body and relieve tension. Miriam also stated that she felt improvements in pain level some days after attending the yoga class. While this was not consistent, she still believed that overall, it was difficult to determine whether the yoga helped to improve her pain.

### ***Conclusion***

Theme Two’s topic highlighted the various treatments and medication endometriotic patients have to endure to aid in alleviating their pain and regulating their other symptoms. Additionally, Theme Two disclosed the lack of options presented for treatment. Theme Two also uncovered the inefficacy of such medical treatments and medications. The lack of consistency in effectiveness of current endometriosis treatments enforce patients to search for non-medical methods themselves which suit their pain levels and condition.

### **Theme Three: Yoga and QOL**

Theme Three focuses on the impacts of yoga and QOL in each of the various domains impacted by endometriosis using the participants’ overall perceived QOL scores and qualitative

data. The Endometriosis Health Profile (EHP-30) is a Health-Related Quality of Life (HRQoL) self-report survey used to assess the wide range of effects that endometriosis can have (Oxford University Innovation, 2016). The domains within the EHP-30 are pain, control and powerlessness, emotional wellbeing, self-image and social support (Oxford University Innovation, 2016). I developed a questionnaire contextually influenced by the EHP-30 and used this prior to yoga starting, a short version halfway through, and then again at the end, to determine whether or not yoga has an effect on reducing endometriosis pain and therefore improving QOL. The data from the endometriosis health questionnaires is presented first, followed by the qualitative data (mental wellbeing, self-image and social support). With the very small number of participants, no statistical claims can be made and the qualitative interviews and journals are used to further explore how the participants perceived the yoga affected their endometriosis and pain, and in turn, affected their perceived QOL.

***Participants’ Endometriosis Health Questionnaires***

Participants were asked to complete an endometriosis health questionnaire at the start of the research in pain, control and powerlessness, emotional wellbeing, self-image, and sexual relationships. The impacts of endometriosis on these dimensions are measured by numerical scores ranging from 0 (best possible health) to 100 (worst possible health) and give indication of the individual’s self-perception of their QOL (Oxford University Innovation, 2016). Table 4 and Figure 2 show the participants’ scores on the endometriosis health questionnaire at the beginning of the research.

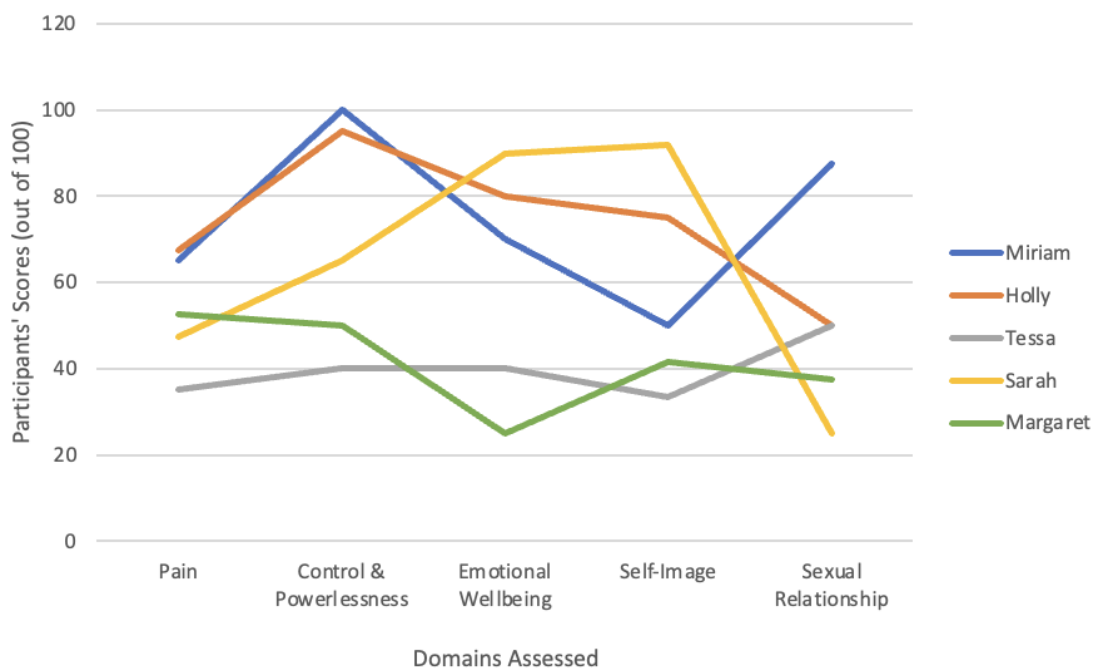
**Table 4**

*Endometriosis Questionnaire Scores Obtained at the Start of the Research (Out of 100)*

QOL Domain	Participants				
	Miriam	Holly	Tessa	Sarah	Margaret
Pain	65	67.5	35	47.5	52.5
Control & powerlessness	100	95	40	65	50
Emotional wellbeing	70	80	40	90	25
Self-image	50	75	33.3	92	41.67
Sexual relationship	87.5	50	50	25	37.5

**Figure 2**

*Pre-test Endometriosis Health Questionnaire Scores*



The average of each dimension is as follows: pain= 53.5, control and powerlessness= 70, emotional wellbeing= 61, self-image= 58.4, and sexual relationship= 50. The average score for pain is approximately at moderate health, as it is around the middle range between 0 (best possible health) and 100 (worst possible health). The median scores of each dimension are as follows: pain= 52.5, control and powerlessness= 65, emotional wellbeing= 70, self-image= 50, and sexual relationship= 50. The scores for pain had the least range between participants compared to the other dimensions. The mean score for control and powerlessness showed a high moderate level. This score was skewed by the scores of Miriam (100) and Holly (95), who scored extremely high scores. The scores of Miriam and Holly showed that their sense of control was very much adversely affected by endometriosis. The average score for the participants' emotional wellbeing also showed a moderate level of health with Holly's score of 90 skewing the average. Self-image also ranged greatly and the average score showed that the participants were again of moderate health in relation to self-image. The average score for sexual relationship was precisely in the middle of the health scale, showing that perhaps in this participant group, sexual health was not a dimension that was impacted greatly. The median score for all of the dimensions shows at least a moderate value, indicating that although these aspects in the participants' lives are not at their worst, these domains have all been significantly affected by endometriosis.

## ENDOMETRIOSIS & YOGA

Six weeks into the research, the participants were asked to complete a shorter version of the endometriosis health questionnaire (five questions, compared to the 25 questions at the start of the research). Only two participants completed this questionnaire, as Holly and Sarah had withdrawn from the research by this time and Margaret had not yet attended any yoga classes so felt that she should not complete the questionnaire. Table 5 and Figure 3 show the participants' scores on the shortened endometriosis questionnaire completed midway.

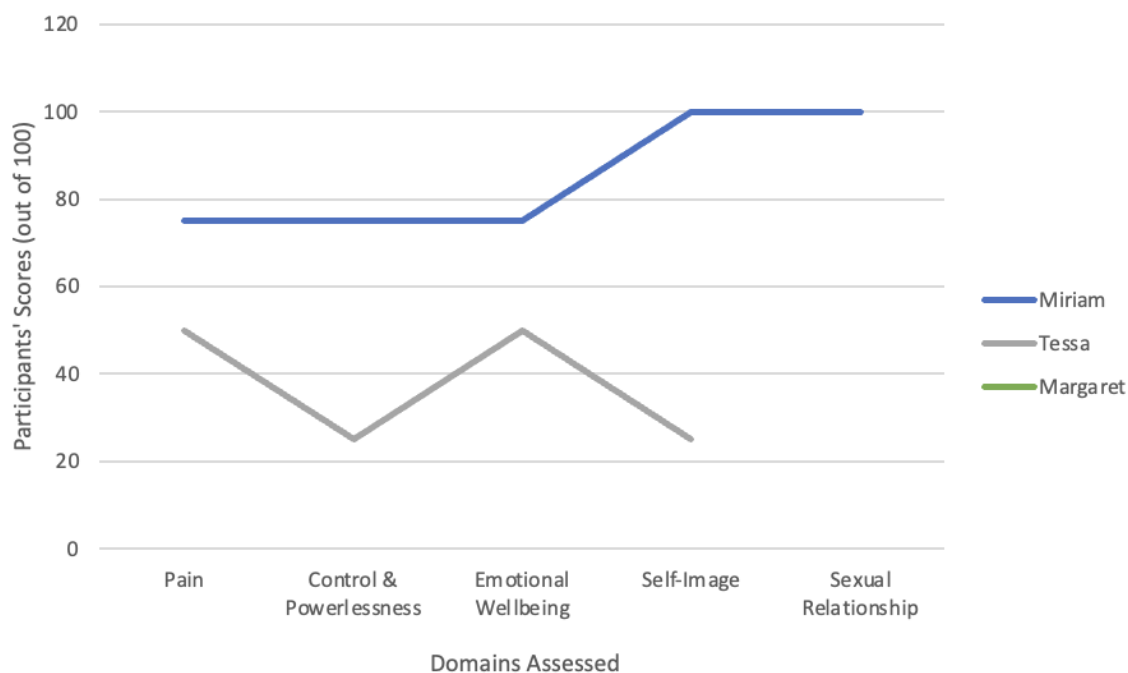
**Table 5**

*Endometriosis Questionnaire Scores Obtained at the Middle of the Research (Out of 100)*

QOL Domain	Participants				
	Miriam	Holly	Tessa	Sarah	Margaret
Pain	75	-	50	-	N/A
Control & powerlessness	75	-	25	-	N/A
Emotional wellbeing	75	-	50	-	N/A
Self-image	100	-	25	-	N/A
Sexual relationship	100	-	N/A	-	N/A

**Figure 3**

*Mid-test Endometriosis Health Questionnaire Scores*



## ENDOMETRIOSIS & YOGA

The average score between Tessa and Miriam for the domains are as follows: pain= 62.5, control and powerlessness= 50, emotional wellbeing= 62.5, self-image= 62.5. Only Miriam completed the questions relating to sexual relationship so the average for this will not be mentioned. The average score for pain increased from the previous questionnaire (53.5), as both Miriam and Tessa's individual scores for pain had increased compared to the first questionnaire. The average for control and powerlessness had decreased by only 3.5 during this time compared to the previous questionnaire. Both participants' individual scores for control and powerlessness had decreased (improved) substantially: Miriam's score decreased by 25% and Tessa's decreased by 37.5%. The average score for emotional wellbeing had increased (worsened) very minimally by 1.5 and interestingly, both Miriam and Tessa's scores on emotional wellbeing had also increased during this midway test compared to their scores at the start of the research. For self-image, the average score increased when participants completed the midway questionnaire. Miriam scored 100 at this time, compared to scoring 50 at the start of the research. This has skewed the average score between the two participants. It should be noted that this change could be related to many things and it would be difficult to pinpoint a specific factor that caused this score to double. Miriam had mentioned during the closing interview that she was not aware how inflexible she really was until she did the yoga classes and so this could possibly be a factor to consider. Miriam's score on sexual relationship had gotten worse between the first questionnaire to this midway one.

When I reviewed the uses and scores of the questionnaires upon analysing the participants' data, I came to believe that the shortened questionnaire given to participants midway through their research seemed to have not been necessary due to the short time period and minimal yoga sessions attended.

The participants filled out the endometriosis questionnaire for the third and final time, at the completion of the research. Miriam, Tessa and Margaret completed the full length of the 25-item questionnaire. Table 6 and Figure 4 show the participants' scores on the questionnaire.

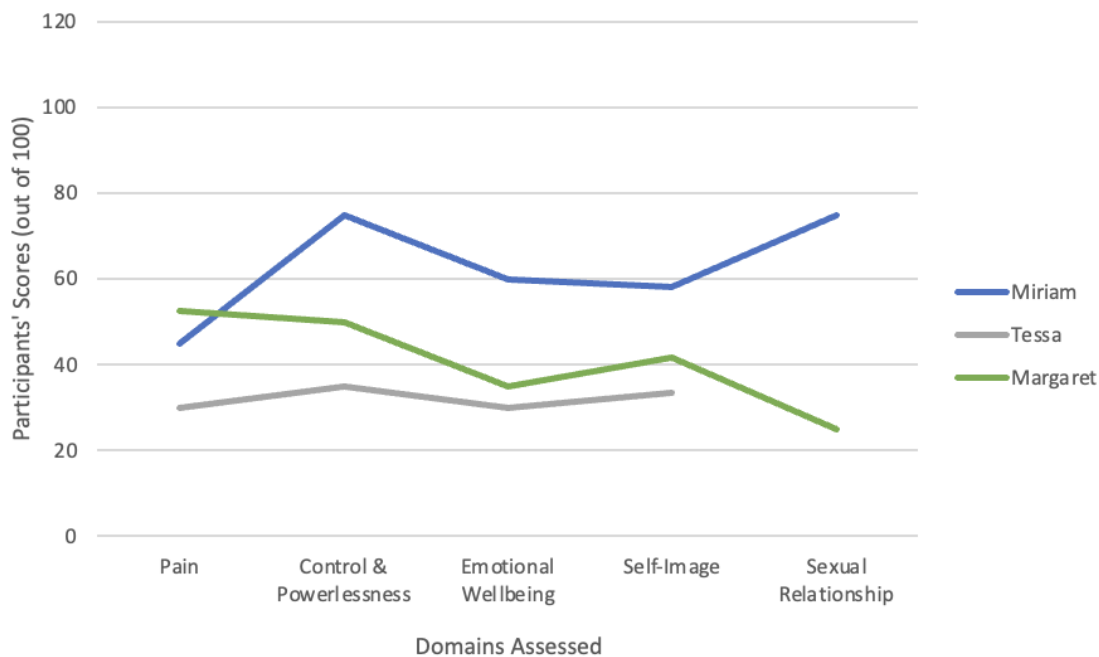
**Table 6**

*Endometriosis Questionnaire Scores Obtained at the End of the Research (Out of 100)*

QOL Domain	Participants				
	Miriam	Holly	Tessa	Sarah	Margaret
Pain	45	-	30	-	52.5
Control & powerlessness	75	-	35	-	50
Emotional wellbeing	60	-	30	-	35
Self-image	58	-	33.3	-	41.67
Sexual relationship	75	-	N/A	-	25

**Figure 4**

*Post-test Endometriosis Health Questionnaire Scores*



The average score for each dimension is as follows: pain= 42.5, control and powerlessness= 53.33, emotional wellbeing= 41.67, self-image= 44.32, and sexual relationship= 50. The median scores are as follows: pain= 45, control and powerlessness= 50, emotional wellbeing= 35, and self-image= 41.67. The average score for sexual relationship was only taken between Miriam and Margaret, as Tessa did not complete the questions in this domain. It was not specified why she had

## ENDOMETRIOSIS & YOGA

not completed this section but as the questionnaire asks participants to answer the questions according to the last four weeks, perhaps it can be insinuated that this did not apply to Tessa. Miriam's pain score had decreased by 45% since the midway questionnaire and 44.85% since the first questionnaire. Tessa's also decreased by 40% since the midway questionnaire and 14.5% since the first questionnaire, but Margaret's pain score had stayed the same from when she did the first questionnaire. The average for control and powerlessness interestingly increased from the midway score to the score at the end of the research. The average control and powerlessness score obtained at the end of the research was much lower than the score at the beginning of the research. This could possibly have been from the other two (withdrawn) participants also being present and scoring with high numbers. For emotional wellbeing, Miriam and Tessa's scores for this domain had decreased from both the midway and the start of the research questionnaire. Miriam's score for emotional wellbeing at the end of the research had decreased by 20% since the midway questionnaire and 145.5% since the first questionnaire. Tessa's score at the end of the research decreased by 40% from the midway questionnaire and 15% since the start of the questionnaire. Margaret's score for emotional wellbeing at the end of the research had increased by 29.95% since the start of the research. Margaret's worsening of emotional wellbeing could possibly be due to extraneous variables. For example, she noted that she and her husband were trying to conceive during this time and that she also had some family-related problems that were occurring during this same time. Looking at the scores of Miriam and Tessa alone, it can be indicated that yoga does have an impact on mental and emotional wellbeing.

The average score for self-image had also reduced at the end of the research from the midway and start of the research questionnaires but the difference in each participant's scores from the end, midway and start of the research varied. Miriam's score for self-image at the end of the research had decreased by 42% since the midway questionnaire but had actually increased by 16% from the start of the research. Tessa's score at the end of the research had increased by 19.9% but was the same as her score at the start of the research. Margaret's score at the end of the research for self-image did not change from her score at the start of the research. Both Miriam and Tessa had experienced an increase (worsening) of scores in self-image midway through the research. Many extraneous factors could be attributed to this, but one possible explanation could be that since the midway questionnaire was given to participants to complete during the time they had only attended two weeks (four classes) of yoga, they may have still been getting used to doing different poses and exercises that their bodies were not used to. So, it would only be expected that they may find some

difficulty in being able to do the poses and being comfortable with the yoga, poses, instructor, etc. In doing so, this may contribute to them having a reduced self-image.

Finally, the average score for the participants' sexual relationship varied throughout the research as the number of participants completing the questionnaires did not always complete them. For example, the average score for sexual relationship at the start was 50 and all five participants completed the questions. During the midway research, only Miriam had completed the question regarding sexual relationship; her score had decreased by nearly half since the midway questionnaire's score upon the completion of the research. Margaret's sexual relationship score was also lower than her first score obtained at the start of the research. With Margaret, it was understood that she and her husband were trying to start a family and so she may have perceived her sexual intimacy to have been less negatively impacted by endometriosis due to her optimism and effort to get pregnant. Nevertheless, the accuracy of all of the participants' scores could be somewhat scrutinised as it should be taken into consideration the many factors that could have influenced the participants to score the way they did. For example, participants could have not answered truthfully about a question/s due to embarrassment or wishing to be a desirable participant, exhibiting demand characteristics (Lynn Institute, 2023).

### ***Summary of Perceived QOL***

To comprehend each participant's changes in perceived QOL over the course of the research, I have included tables and figures of the participants who did not withdraw from the research. Only the three participants' (Miriam, Tessa, and Margaret) endometriosis health scores were constructed and displayed onto tables and line graphs as they were the ones who continued to participate throughout the research. Therefore, the length of time they practiced the yoga could be analysed and assessed in line with any changes seen in their endometriosis questionnaire scores.

Table 7 and Figure 5 show Miriam's endometriosis health questionnaire scores from the start, middle and end of the research.

**Table 7**

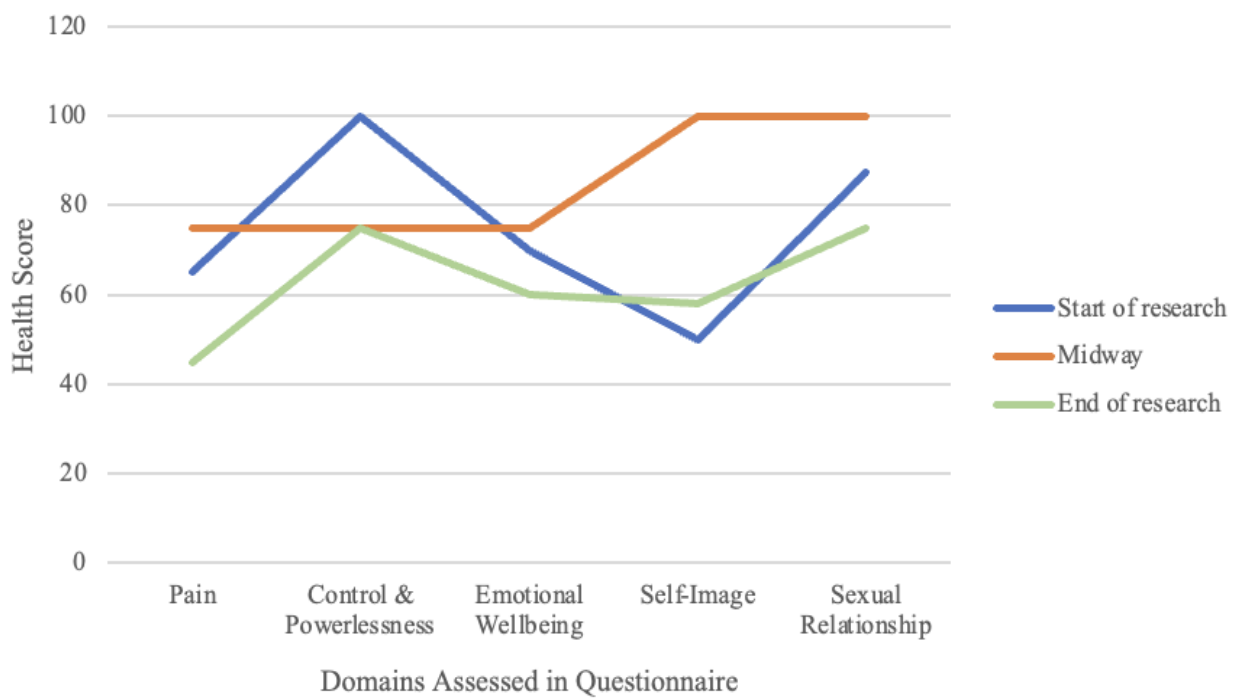
*Miriam's Endometriosis Health Questionnaire Scores*

Time of Research	Domains Assessed				
	Pain	Control & Powerlessness	Emotional Wellbeing	Self-Image	Sexual Relationship
Start	65	100	70	50	87.5
Midway	75	75	75	100	100
End	45	75	60	58	75

*Note:* The scores on this table are values out of 100.

**Figure 5**

*Miriam's Endometriosis Health Questionnaire Scores*



*Note:* The scores shown in this figure indicate values out of 100.

## ENDOMETRIOSIS & YOGA

Table 8 and Figure 6 shows Tessa's endometriosis health questionnaire scores from the start, middle and end of the research.

**Table 8**

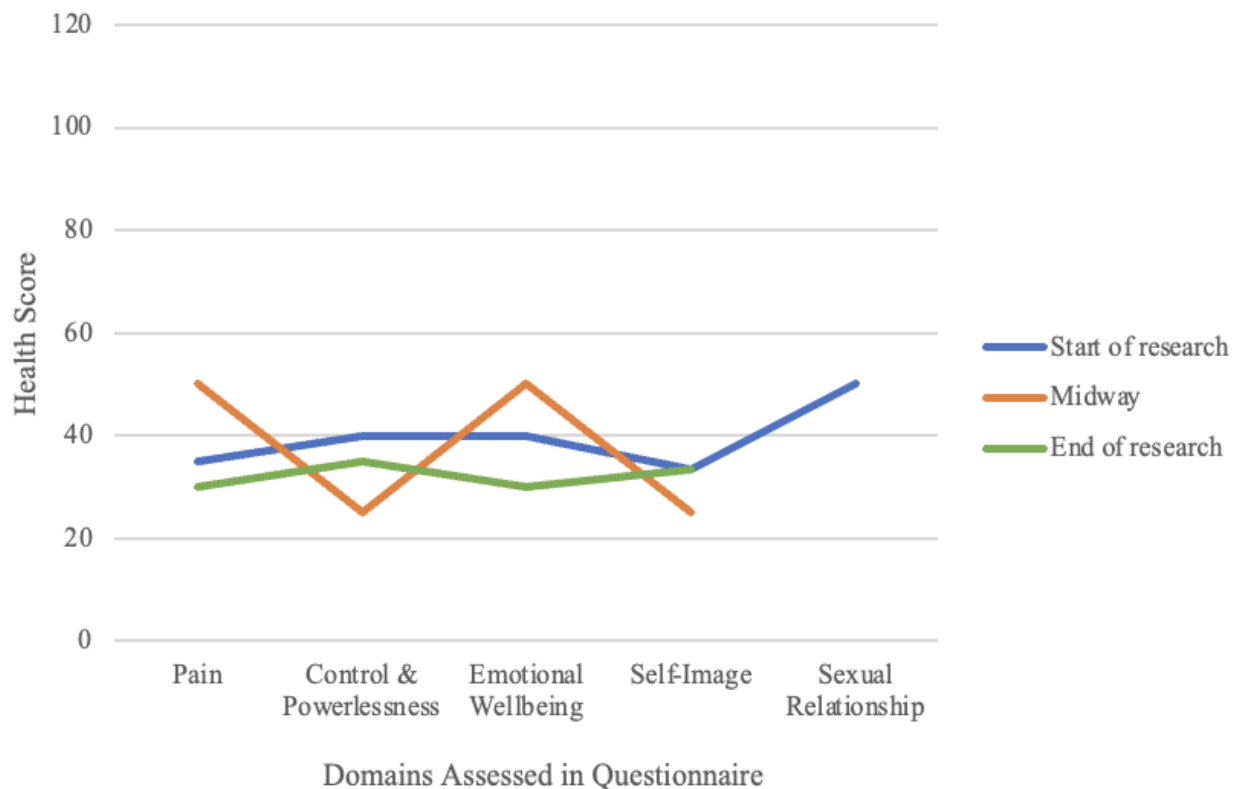
*Tessa's Endometriosis Health Questionnaire Scores*

Time of Research	Domains Assessed				
	Pain	Control & Powerlessness	Emotional Wellbeing	Self-Image	Sexual Relationship
Start	35	40	40	33.3	50
Midway	50	25	50	25	N/A
End	30	35	30	33.3	N/A

*Note:* The scores on this table are values out of 100.

**Figure 6**

*Tessa's Endometriosis Health Questionnaire Scores*



*Note:* The scores on this figure are values out of 100.

## ENDOMETRIOSIS & YOGA

Table 9 and Figure 7 shows Margaret’s endometriosis questionnaire scores from the start, middle and end of the research.

**Table 9**

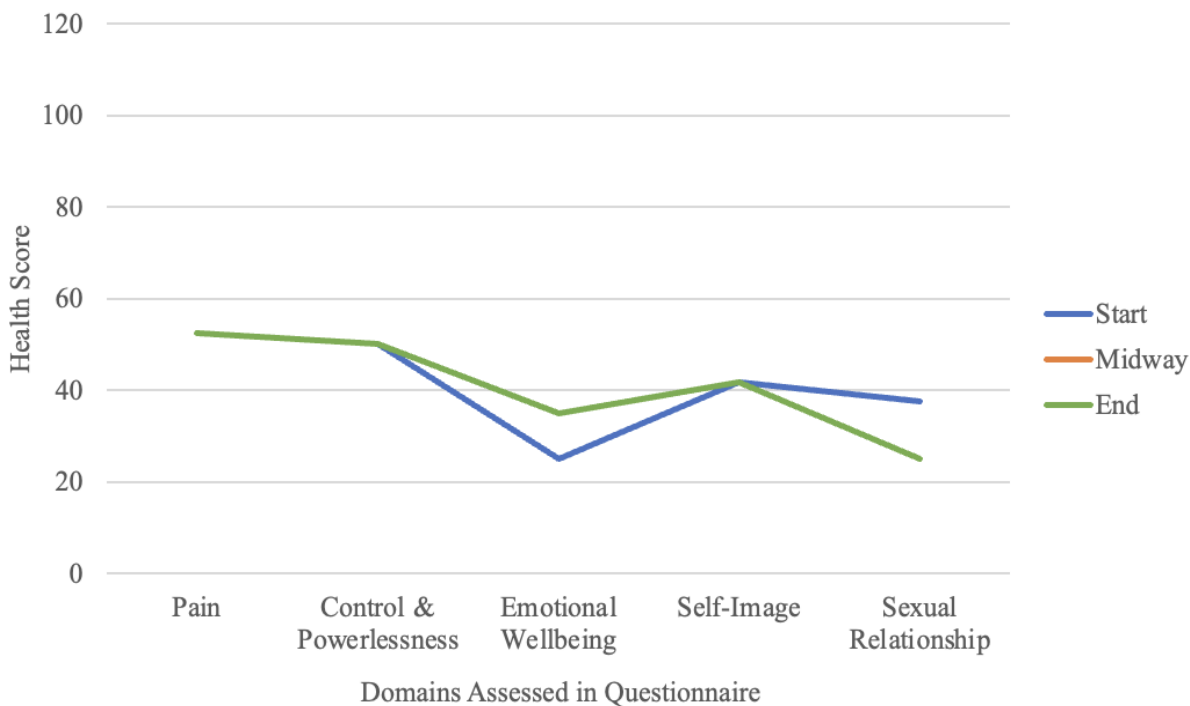
*Margaret’s Endometriosis Health Questionnaire Scores*

Time of Research	Domains Assessed				
	Pain	Control & Powerlessness	Emotional Wellbeing	Self-Image	Sexual Relationship
Start	52.5	50	25	41.67	37.5
Midway	N/A	N/A	N/A	N/A	N/A
End	52.5	50	35	41.67	25

*Note:* The scores in this table are values out of 100.

**Figure 7**

*Margaret’s Endometriosis Health Questionnaire Scores*



*Note:* The scores in this figure are values out of 100.

### *Mental Wellbeing*

As the participants reflected on their experience with the research and yoga, they commonly spoke about the effects practicing yoga had on their mental health. The two participants who regularly attended the yoga sessions, Tessa and Miriam, spoke about the benefits of yoga and the complexities of living with pain and understandings of mental wellbeing. Miriam said during her closing interview:

*“And being **present with our body**. Because again, when you’re in pain, like it’s almost like, the **dissociation** from your body causes you pain and then the pain also makes you want to dissociate from your body. So, it’s like a cycle but the **yoga kind of breaks that**.”*

Miriam stated that being in pain makes her want to disengage with her body and to feel removed from the situation and feeling all together. In doing yoga, she had learned to be more mindful of her body which helped in withstanding the pain and therefore reduce her perceived pain level, breaking the cycle.

Tessa also spoke about how the yoga had helped her to improve her cognition as well as mental health: *“during the session I can definitely focus and concentrate...felt calm and peace. It was quite refreshing after the session”* and *“I would feel calm during the session or maybe after doing yoga. The following day, the following days, I felt great”*. During the closing interview when I asked her if she noticed any positive emotional, psychological and physical changes since doing the yoga, she pointed to her chest and said, *“my soul generally”*. Though not a grand gesture, this pointing-to-the-chest action was very powerful and emphasised just how much she was impacted by the yoga and research overall. By her saying ‘soul’ rather than referring to her mental wellbeing, this indicated that the yoga positively affected her to a greater extent than just her mental health and cognition, but also impacting the very essence of her as a person, her spirituality.

Writing in the journals was also an aspect the participants mentioned made a positive impact to their mental health. Tessa claimed that regularly self-reflecting on her pain, mood and emotions by writing in her journal helped boost her mental health as she was able to see her progress throughout the research and practice mindfulness through looking back on the reflections. She said, *“I’m dedicated to do the trial because I want to see if there are any improvements or changes to my body. And I think that’s a dedication for me. And writing down something, it helped me to do like a small reflection in a day”*. Miriam also mentioned that prior to the research, she used to not want to acknowledge what she felt that day because she would not want to face and remember it.

Contrastingly, she found journaling beneficial as she was able to track her pain patterns, notice any

## ENDOMETRIOSIS & YOGA

triggers, as well as other aspects that were affected (e.g., emotional and psychological) when she was in pain.

Margaret felt that doing yoga had helped with her mental health, despite doing yoga by herself, not attending the yoga classes in-person. Margaret did not have a positive experience with the yoga classes due to disagreeing with how the yoga instructor, Samantha, conducted the classes and how she approached the participants. Margaret mentioned that she was apprehensive and did not feel comfortable with how the teacher pushed her beyond her physical ability and also would not communicate before physically pushing her into a deeper position. Margaret attended two yoga classes and became occupied with work so she then continued to practice yoga alone at home through the recorded videos I would send her of the yoga classes. During the closing interview, Margaret expressed that she enjoyed doing the yoga classes herself at home: *“I found that when I was doing the classes at home and just pushing it as far as I could...I just enjoyed it a lot more”*. Margaret also found the journaling aspect of the research beneficial for her mental health:

*“I found the journaling quite helpful. Just to see for me like when pain actually starts, when it gets worse. Because I think I’ve always roughly known or like you know, half of the month I feel a bit crappy and then you know like, for three or four days I feel really shit. But actually seeing exactly when, was really interesting. And then just noticing when I started to take medication and things like that so I could track it. Like all of that was just stuff that I hadn’t actually done before so that like, that part of it was really interesting for me.”*

### **Self-Image**

Yoga also had a positive impact on the participants’ self-image. This was particularly evident for Tessa and Miriam. Both participants attended the yoga classes regularly, only missing out on a few classes. During their closing interviews, they both shared how the yoga made them feel more positive and appreciative of their bodies and abilities. Feeling this way, they were able to alter their mindset about their endometriosis and pain by reducing self-blame and instead, directing more focus on what their bodies are able to achieve. Miriam said:

*“I think when we were doing the yoga like, we would have just yeah, like, kind of positive talk around our bodies rather than...which kind of like, goes against what I have in my head when I’m sore. So, I feel like I’ve noticed that. It’s like more positive talk about my body and like, “look what I can do” or yeah, “look how much it’s improved” or like, you know, when even Tessa would say like, “thank you (body). You did a good job”, things like that. That influenced me to definitely think that way rather than, “why can’t you be normal?!”.”*

## ENDOMETRIOSIS & YOGA

Practicing body positivity has helped the participants also feel more comfortable and confident in their bodies. Miriam told me during her closing interview that she really appreciated how the yoga instructor, taught the classes. She said that Samantha would specify how each person has different limits and she would give variations of poses to each participant according to their limits and abilities. Doing this Miriam felt, helped to make her feel comfortable in her body.

Some aspects of the yoga classes were consistent throughout the research, such as the sun salutations. Tessa said, *“I particularly like the sun salutation. Because we did it from the beginning to the end and I was not...I was not very comfortable following her instructions or because I’ve never done that before...yeah, but eventually I felt more comfortable doing that. I could feel, I don’t know...I just feel more comfortable doing that. Sometimes when I’m at home I still do that”*.

Evaluating how Tessa explained finding her comfort and self-confidence in the sun salutation, it seems that as the exercise was a constant practice, this allowed her to work towards progressing in the poses. Thus, improvements in this are seen as a sense of achievement and builds confidence, strengthening her self-image.

### ***Social Support***

Another aspect tied to QOL that yoga had a positive impact on was social support. During the initial interviews, some of the participants had disclosed that no one else in their life endured chronic pain or endometriosis and so they did not have anyone to relate to. Tessa explained, *“no one in my family has the issue, not even my friends. So, I’m kind of like, I don’t know what to do, no one really understands...the pain that I’m going through”*. Expressing this lack of social support and relatability in their lives because of endometriosis, a few of the participants stated that they were looking forward to associating with and being around other women who have endometriosis. During the initial interview with Miriam, I had mentioned that the research would be a good opportunity to connect with other women living with endometriosis. To which she replied, *“I think so too. I think just even knowing that you’re like, yeah, have other people that are in the same boat with you that are kind of like, doing the same things as you- that I feel like, that already feels like healing in a way.”*

Considerations surrounding social support was explored during the closing interviews and in particular, Miriam and Tessa discussed this topic more extensively. Miriam described how the yoga classes felt very welcoming which helped her to feel more comfortable and therefore enhanced her yoga experience. She said, *“everybody who was involved as well as really wanting to be there which is really nice. Makes a big difference...I feel like, and just like, friendly and warm. So, I felt*

## ENDOMETRIOSIS & YOGA

*really comfortable every single time coming in and I really wanted to and yeah, I mean honestly like, such a positive experience*". Analysing what Miriam said, it can be argued that it is not actually the yoga itself and the poses taught during the classes that created a positive impact on the participants' social support. Rather, it was the fact that there was a class with other endometriotic women and a yoga instructor who were very welcoming and understanding of each other's pain and condition. It seems that being around others who are experiencing the same situation as you or being around those who are understanding of your endometriosis and pain can make people feel like they have social support. Being around others with the same condition, Tessa expressed that she felt less lonely. She stated, *"I think the other take away for me is that since we did that (yoga) in a group, we have the participants experience the same thing- a similar issue. So, I felt more in common...something that was in common though it was not a good common. I'm not alone"*. Looking at these responses from participants regarding social support, it can be determined that the yoga class, not yoga itself, had improved social support for these endometriotic patients.

### **Conclusion**

Theme Three's topic of the relationship between yoga and QOL yoga had a positive impact on mental wellbeing, self-image and social support. Nevertheless, the scores produced by the endometriosis scores showed that the improvements in these three aspects were not linear, as some participants had experienced both a decrease and increase in scores in the domains throughout the research (e.g., emotional wellbeing, self-image). The contradiction in findings obtained from the qualitative methods (journals and interviews) and the endometriosis health questionnaire highlights the difficulty in determining whether the participants' reflections of their experience should be prioritised over a quantitative questionnaire, or vice versa.

### **Theme Four: Benefits of Yoga on the Body**

The practice of yoga encourages a union between the body and the mind (McCall, 2013). While endometriosis is a medical condition that has physiological implications on the affected individual, such implications can also influence the individual's psychological wellbeing, as well as the person's mental health having an influence on physical health (Smrdu, 2022). Both yoga and the biopsychosocial model view a person's physical body and mental wellbeing as being intertwined and interconnected. Therefore, it was expected that yoga would have some sort of impact on not only the participants' mental health but also physical health. Participants said practicing yoga helped flexibility, muscle toning, and improved physical capability. The mental health benefits are covered in Theme Five.

### *Flexibility*

Tessa and Miriam had both mentioned flexibility and how theirs had improved since practicing yoga throughout the research. Both had explained how they did not realise how inflexible they really were until they started doing the yoga classes. When I asked Miriam during her second interview if the yoga sessions were what she expected, she replied:

*“Yeah, I think just the fact that I didn’t expect that I wasn’t going to be as flexible. Cause I thought I was flexible. Yeah, I thought that I was like, my body was like... I know in my pelvic area like, okay it’s tight...but everywhere else when I’ve done yoga, I thought I was like, fine, but it was good in terms of like, it was a challenge for my body. And I definitely noticed a major difference with my mobility and flexibility.”*

Tessa had also realised her inflexibility once she started the yoga classes. She mentioned that practicing the yoga challenged her body in terms of its flexibility and made her reflect upon this as something she would like to work more on. She stated, *“I found that my pelvis or back (muscles) are not as flexible as I thought. So, this is something I would like to work on”*. Tessa said that for her flexibility, the triangle pose was one that she found challenging yet rewarding. Having done it a few times throughout the yoga sessions, she saw improvements in her ability to do the pose and was surprised in her body’s flexibility to do the pose. Referring to the triangle pose, she said, *“I was quite surprised that I was able or flexible to do so”* and *“I can see how I improved, more comfortable and confident in doing that”*. Tessa had also mentioned practicing the frog pose in her own time to improve pelvic flexibility<sup>7</sup> to see if this could help with pain relief. She had not noticed an instant significant decrease in her pain from doing the frog pose, however, she explained that her lower body would feel more relaxed and less tight. Tessa had only practiced the frog pose since the research started and was not consistent in doing so. So, it would be interesting to see if her pain would decrease if she were to do the frog pose more consistently and over a longer time period, as the pose helps with pelvic tension release and flexibility.

### *Muscle Toning*

Another aspect as to how yoga affected the participants physically was through muscle toning. Miriam in particular described how she noticed a change in her appearance. She noticed herself as having a “fuller” figure and had gained five kilograms, something that she had been trying to achieve for a long time. She explained:

*“I did gain a butt! I was like hey, that is the yoga because there’s nothing else I do. But I think I did **gain muscle**. And I also- so **I had been trying to gain weight** for a really long*

*time, and I was like stuck at this weight and it was just annoying because it was like I wanted to make sure I was more full. And yeah, right before my procedure, they weighed me and they were like, they showed me the number and I was like, “that’s my jacket, like, let me just take off my jacket”. And then it wasn’t my jacket. And I was like, “I’m stoked!”. So, I think it also helped me gain muscle.”*

Aside from Miriam, no other participants mentioned their bodies benefitting from muscle toning from the yoga. Miriam spoke about her weight gain through a positive stance, whereas usually there is negative stigma around weight gain (Wellman et al., 2018). If Tessa and Margaret did gain weight or muscle from the yoga, this association with weight gain may be a reason as to why they did not mention it in their journals or interviews. Otherwise, it could just be that they did not notice any muscle toning through the yoga.

### ***Physical Capability***

Yoga had improved the mobility and physical capability for Tessa and Miriam despite them finding it challenging. Finding the yoga challenging actually motivated them more to try their best and push their physical capabilities. Miriam expressed that going to the yoga classes regularly, she could see her mobility and ability improve, motivating her to keep attending the yoga classes and also practice poses at home. When asked what made her practice some poses and exercises in her own time, she said, *“I think just it feels so good afterwards that you’re like, “I just want to re-experience that positive feeling. I think that’s just why I did it. It feels yeah, it feels good. You know, seeing your body improve and doing the actual movements and getting out of your brain for it”*. From this statement, she explained that because she felt good from seeing improvements, this made her continue in practicing yoga and certain exercises such as the sun salutations (as she mentioned in her closing interview). This statement from Miriam also gave some indication that yoga can have a positive impact on both the body and the mind. Miriam also acknowledged this: *“I was saying like, there are more challenging times and I feel like it was the right amount of challenge. Where like, you know, it’s okay if your like, leg hurts a little bit and it’s like tough to do that. But it’s good for you and then it’s nice. So yeah, I feel like definitely both mental and physical (benefits).”*

Similar with Miriam, Tessa also described how she enjoyed that the yoga was challenging for her at times and that seeing improvements in her ability pushed her to continue with the yoga. She explained, *“It’s challenging but in a good way. And there’s some poses I’ve never done before, and I’m happy that I was able to do it”*.

### *Short-Term Pain Relief*

It was difficult to conclusively explore if yoga directly impacted pain. Tessa and Miriam both explained that during the days they would be in pain and they would attend the yoga class, sometimes they experienced a decrease in their pain level after the class. This was not consistent and their pain did not always decrease after yoga. Miriam said, “*there were actually moments where after yoga it got better right, but I just don’t want it to like, be...it’s not like the yoga wasn’t working...it’s just that there might be some many other things going on*”. When asked if the yoga affected her pain levels, Tessa responded, “*in terms of pain, I don’t see a huge difference because from time to time, I can see that the cycle is that before the period, I still feel the pain- sometimes I still need to use a hot bottle to make me feel better. It’s still I think...it’s impossible if I do yoga for two months and then I would see (changes)*”. Expanding on this, Tessa nevertheless explained that she still would experience a decrease in pain after yoga and sometimes days after doing yoga: “*...after doing yoga, the day, following days, I felt great*”, and also saying, “*I don’t see a huge difference but it seems like right after the yoga session it (pain) seems slightly improved*”. Speaking to both Miriam and Tessa, both explained that while they experienced some pain relief after doing yoga, there were still too many other factors and inconsistencies for them to state that the yoga significantly impacted and decreased their endometriosis-associated pain.

Margaret also stated that she did not see a significant difference in her pain levels during and after doing the yoga and completing the research. She explained how since her initial interview, she was undergoing many things medically which were associated to her endometriosis. Prioritising starting a family, she was getting many more tests and scans done related to her condition and fertility, which at times caused her to be in pain. Having numerous other factors causing her pain, it was difficult to separate evaluating the impacts of yoga on her pain and endometriosis from all of these other factors. Margaret said:

*“At the same time, I had a lot of scans done and the like, transvaginal ones with the camera. And they caused quite a lot of pain. And so sometimes I was having them done around the same time as I was doing yoga. So, I think I probably have had increased pain over the time that your study has been done, but I really don’t think it’s related to the yoga and I didn’t ever feel like you know, directly after the yoga that I felt in pain...so I don’t think I saw a decrease in pain, but I don’t think yoga caused any kind of increase in pain...I think pain levels have been more up and down than they were before and I think that is more to do with external factors like the scans, etc.”*

As the cause of endometriosis is still unknown, this makes it difficult to explore pain management methods that directly target the source of the symptoms as there is no definitive source to target. This issue also applies to endometriosis-associated pain in that the source of the pain varies across each individual, and the symptoms, severity, and various other extraneous variables all play a part in forming the individual's pain experience. This then makes it very complex to investigate pain management methods that reduce pain for all endometriotic women. Perception of pain is explored more in Theme Six.

### ***Conclusion***

Theme Four covered the benefits that yoga may have had on the participants' physical health and bodies including, flexibility, muscle toning, physical capability and short-term pain relief. The participants also explained how the yoga was at times challenging, but that this increased their motivation to progress physically (flexibility, strength, balance), also indicating that the physicality of yoga had positive implications on the participants' psychology through heightening their motivation. In regards to their endometriosis and pain, the participants mentioned how at times, they would feel slight improvements in their pain level after doing the yoga but this was not consistent and the pain relief was only temporary.

### **Theme Five: Benefits of Yoga on Mental Health**

One of the main teachings of yoga is to practice psychological interventions such as mindfulness (Evans et al., 2019). Thus, it can be somewhat expected and hoped that the participants' mental wellbeing were affected for the better. The participants reported that their mental health had been positively affected by the research and yoga.

### ***Confidence***

Two out of the three participants who practiced yoga throughout the research mentioned that they felt an improvement in their confidence. The concept of confidence is broad and, in this regard, the confidence in which the participants referred to was self-confidence and confidence in physical ability to do yoga. For example, Tessa described how she would share her yoga and research experience with her family, saying, "*I would share my experience with my friends and family like, 'hey...' and then I will share the photos with them*". By Tessa sharing her photos and discussing her yoga experience with people in her life this is a big indication that she felt comfortable, confident, and even proud of her ability and participation in the yoga. Miriam also went through a similar situation in which she also shared her yoga experience with people in her life- she taught her

## ENDOMETRIOSIS & YOGA

husband and family some of the yoga poses. She said that she had practiced the sun salutation at home many times and had also taught her family: *“taught my family as well...yeah and my nephew. Actually, I have a photo of my nephew doing the downward dog!”*

The participants had not regularly practiced yoga before the research and so they were outside of their comfort zones to an extent, doing poses and exercises that tested their physical abilities. Tessa expressed that she gained confidence in her physical ability to do yoga, such as in doing the sun salutation: *“I enjoy it (sun salutation). Yeah, because I can see...I can see how I improved, more comfortable and confident in doing that”*. In regularly practicing the sun salutation, she was able to see her improvements and therefore gain confidence. Also, Tessa expressed that because the other participants and yoga instructor were aware of her illness, she felt comfortable and confident in asking questions or requesting variations to poses: *“yeah, not embarrassed to ask”*.

### **Control**

Another aspect in which the participants mentioned was positively impacted by yoga was control. Before the yoga was incorporated into her life through the research, Miriam would adapt her lifestyle to accommodate her endometriosis symptoms and pain - when in pain, she would normally let the pain consume her. She stated, *“I just thought like, well, I feel like shit and this is how it is. And this is what I feel right now”*. Since starting the research, she reported practicing yoga and meditation more regularly implementing in her day-to-day life even when she felt pain. She had disclosed that she would sometimes meditate if she was in pain and also try to change her mindset to think about what she could do to be more in control of her pain and not feel so helpless. She said, *“being able to say like, okay, I could do some things and even when it was uncomfortable, I could notice this...”*

Tessa also exclaimed that since starting the research and incorporating yoga into her life, she has become more aware of her health and trying to maintain a healthy lifestyle. She mentioned how doing yoga made her more aware of her health and flexibility of her body, reflecting on how her health was not always a top priority. She said, *“I just want to try and maintain my healthy lifestyle, trying to do a little bit. I mean, I have a really bad habit that I really want to work on...but yeah, I, for example, for my eating habit, or try to...try to push myself to do exercise and stuff I think and yeah...I need to do more”*.

### **Independence**

Gaining independence through the practice of yoga was also described by Tessa and Miriam. An exercise such as the sun salutation, was an exercise that the participants repeated every

## ENDOMETRIOSIS & YOGA

session. This helped Tessa and Miriam to feel comfortable in doing the exercise, getting them more familiarised with the sun salutation. Getting more familiarised with the sun salutation, this increased their independence bit by bit and allowed them to be able to practice the exercise by themselves outside of the yoga class in their own time. The yoga instructor, Samantha, was also accommodating to every one's individual ability. As we discussed prior to the starting the research, she was to give variations of poses to the participants to better suit their capability and their limits. For example, Miriam mentioned, *“even having the blocks and being like, “if you wanted this, you do it this way or do this position”*. *And so, it gave us the option for how we can do it with our body”*. Giving these variations or different levels of difficulty of poses allowed the participants to be able to practice such poses in their own time. As the participants were able practice at home, this helped to increase their independence in doing yoga by themselves. Miriam said, *“I definitely did do them. So that's why I feel like that, at least, will be something that I'll definitely carry. And then also, even the things that Samantha told us when we're like working, like putting your shoulders down, hands behind your back, things like that. They were easier to implement than like maybe doing like the whole thing”*.

### **Conclusion**

Theme Five covers the benefits that yoga had on the participants' mental health from the research. Participants mentioned improvements in their confidence, sense of control and independence through the practice of yoga and how the classes were taught by Samantha, the yoga instructor. As endometriosis and psychological wellbeing interdependently affect one another, these improvements can still be regarded as a step forward in helping deal with endometriosis and pain.

### **Theme Six: Yoga and Perception of Pain**

In Theme Six, the impacts of yoga on the participants' endometriosis and pain are further explored, going into detail how yoga had influenced pain perception specifically. Endometriosis and pain are very subjective and whether or not yoga had any influence on the participants' perceptions of pain and to what extent, did vary across the women. In addition, how each participant lived their lives outside of the yoga classes and research was different. To obtain an understanding of how the participants anticipated yoga as influencing their endometriosis, this required them to reflect deeply and openly share their experience with me. This section begins with the results from the daily pain scales followed by their reflections.

**Participants' Daily Pain Scales**

The participants recorded their daily pain level on an NRS pain scale inside their journals. The NRS ranged from '0- no pain at all' to '10- worst possible pain'. Each participant's NRS pain scores were collected and developed into line graphs showing their daily pain score for each week. Table 10 and Figure 8 show Miriam's median and mean pain scores over the course of the research.

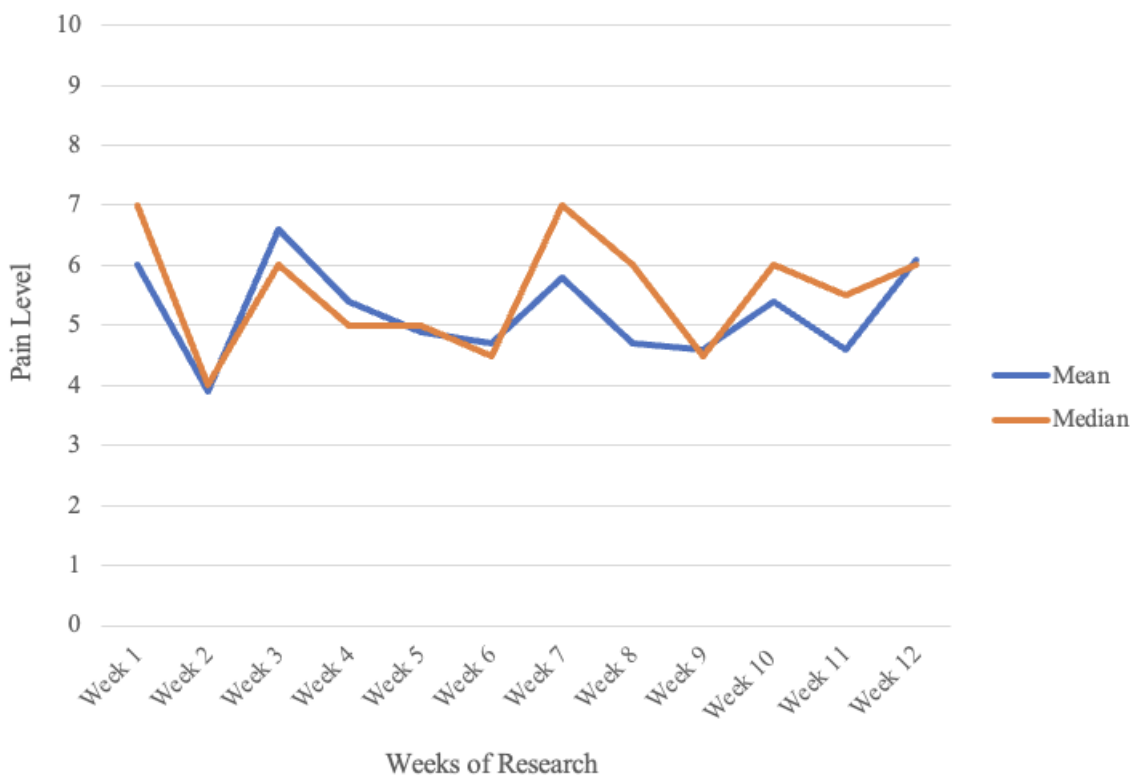
**Table 10**

*Miriam's Mean and Median Pain Scores*

Pain Level	Week of Research											
	1	2	3	4	5	6	7	8	9	10	11	12
Mean	6	3.9	6.6	5.4	4.9	4.7	5.8	4.7	4.6	5.4	4.6	6.1
Median	7	4	6	5	5	4.5	7	6	4.5	6	5.5	6

**Figure 8**

*Miriam's Mean and Median Pain Scores*



Miriam's scores show spikes in her pain levels but unlike Tessa and Margaret, Miriam's average pain level is higher. So, when she experiences spikes in her pain levels and then a decrease,

## ENDOMETRIOSIS & YOGA

her pain is never completely gone. The lowest pain level she experiences is an average of four. As the research went on, her average and median pain level slightly increased. Should the yoga be effective in decreasing pain, the average pain level should decrease as the research goes on. Rather, such as in Miriam's case, her average pain level actually increased, although minimally. This can be seen in week 6, 9 and 11, where the (average) lowest level of pain she experienced were 4.7, 4.6 and 4.6.

Table 11 and Figure 9 show Tessa's median and mean pain scores over the course of the research.

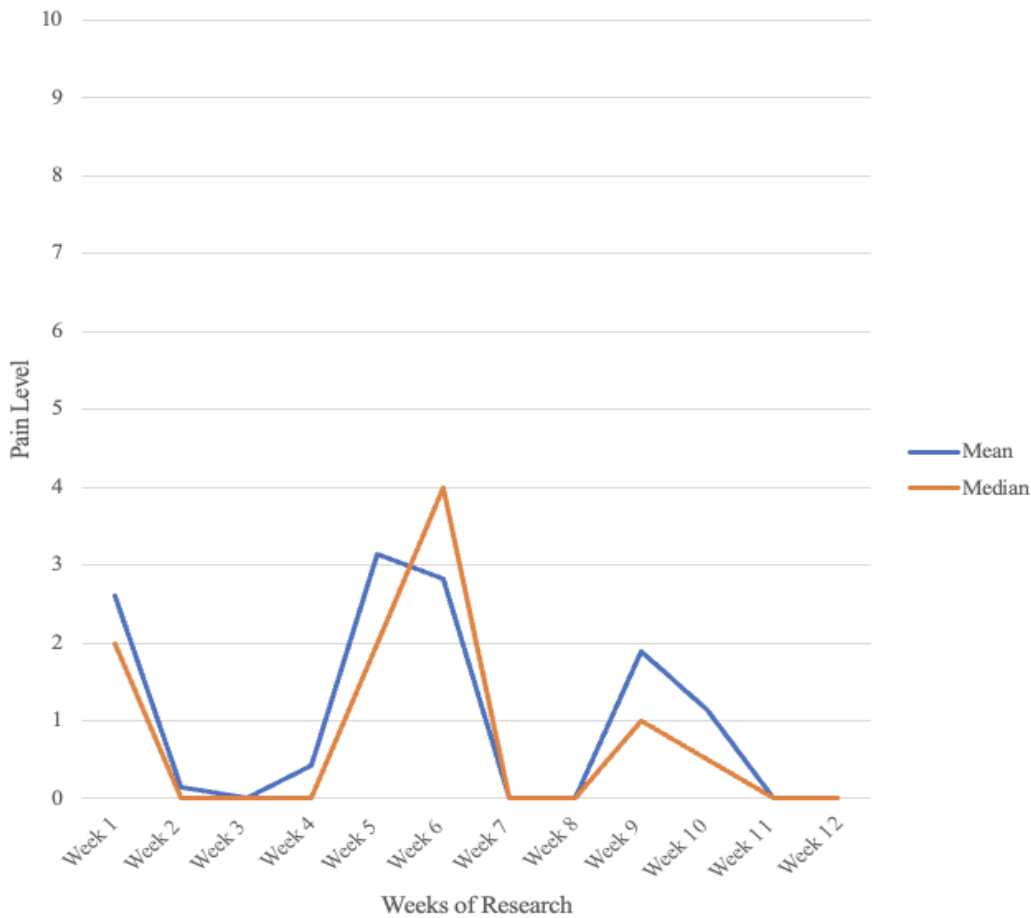
**Table 11**

*Tessa's Mean and Median Pain Scores*

<b>Pain Level</b>	<b>Week of Research</b>											
	1	2	3	4	5	6	7	8	9	10	11	12
Mean	2.6	0.14	0	0.43	3.14	2.82	0	0	1.9	1.14	0	0
Median	2	0	0	0	2	4	0	0	1	0.5	0	0

**Figure 9**

*Tessa's Mean and Median Pain Scores*



Tessa's graph shows that out of the three participants, she experiences the longest time not experiencing any pain. For example, when her pain level is 0, this lasted for about one week, until her pain levels start to increase slowly and she experiences a spike. When she experiences pain, she feels them for a shorter amount of time, unlike Miriam, whereby she experiences at least a low level of pain all of the time.

Table 12 and Figure 10 show Margaret's median and mean pain scores over the course of the research.

**Table 12**

*Margaret’s Mean and Median Pain Scores*

Pain Level	Week of Research											
	1	2	3	4	5	6	7	8	9	10	11	12
Mean	4.6	0	0	1	6.3	3.3	1.6	0.3	5	2	0	3
Median	4	0	0	0	5	3	3	0	5	3	0	4

**Figure 10**

*Margaret’s Mean and Median Pain Scores*



If the yoga was to improve the participants’ pain, the pattern of pain could be seen to decline. All of the participants seemed to experience spikes in their pain levels, increasing their mean and median pain levels for one week and then slowly decrease the next week. These spikes were expected as with endometriosis, it can be common for women to experience dysmenorrhea before, during, or after menstruating (Itani et al., 2022). This was evident for Margaret; for example, in her journal entry, she noted that at the end of week four, her period was late but she began to feel pain. In week 3, she had 0 pain all week and at the end of week four she started to feel low level pain (3, 4). Throughout week five her pain began to increase, starting as low as ‘5’ at the

beginning of the week to experiencing level 8 pain the last few days of week five. She also noted that as her pain intensified over the week, her “*cramps are severe*”, “*unable to stand up straight*” and, “*using toilet every hour*”. Over week six and week seven, her pain levels slowly decreased down to 0 by the end of week seven. At the very end of week eight and the start of week nine, she started to feel pain again. Her pain increased rapidly to a moderate-high moderate level, going back-and-forth between 9, 8, and 7, and she started to menstruate. This helps explain the spikes seen in the participants’ line graphs and demonstrates how when the participants are about to menstruate, their pain levels usually tend to intensify.

The participants’ data and the patterns in their line graphs clearly support the notion that endometriosis and pain are very subjective experiences. No two individuals experience endometriosis and perceive or experience pain the exact same way. The daily pain scores recorded by the participants may have been shaped by various extraneous variables outside of the research, many of which are out of my ability to control. These are factors such as diet, exercise, sleep, other medical conditions, social life, and psychological wellbeing. Thus, there are complexities in being able to clearly determine whether yoga really does have an impact on endometriosis and pain, and if so, to what extent.

### ***Participants’ Reflections on Yoga Experience and Impacts on Endometriosis***

It is not possible to say conclusively if yoga had any effectiveness in being a method of pain management for endometriosis pain due to small sample size, but the participants’ data sets showed that there were no significant changes in the participants’ pain levels from the start to the end of the research. Despite this finding, from analysing the participants’ journals and interview data, and their sense-making of pain, it shows that living with chronic pain is multifaceted. For example, in Miriam’s journal, she wrote: “*did take painkillers to manage the pain when it came but didn’t help*”, “*pain a lot worse at night- was out for most of the day*”, and “*zero energy*”. Writing these in her journal as the research went on, it showed that she was still feeling pain, sometimes intense pain, even when she was practicing yoga twice a week. When she was asked to elaborate on her yoga experience and how she thought it affected her pain during the closing interview, she also explained that she did not feel that yoga made a significant difference in her pain level. She said, “*not as much maybe, it won’t show like with the pain. Yeah, but there’s so many factors. So that’s probably why...*” and, “*there were actually moments where after yoga, it (pain) got better right, but I just don’t want it to like...it’s just that there might be so many other things going on*”.

## ENDOMETRIOSIS & YOGA

In Tessa's journal, she also noted down some things which indicated that the yoga did not significantly improve her pain. Throughout the research, Tessa frequently recorded issues with sleeping when in pain, she found it difficult at times to fall asleep, stay asleep, and wake up due to the pain. Her problems with sleeping due to pain did not seem to improve as the research went on and she practiced yoga consistently twice a week. Tessa started her working at a new job as part of her university placement within six weeks of the research starting. Around eight weeks into the research, she wrote down in her journal that she had felt pain during work and despite her manager telling her to have a rest, she refused to as she did not want "*others to feel that I'm weak*". She also stated in her closing interview: "*during my placement I also had times I felt really painful. And I, yeah, it was...I had a stomach ache and, and, the pelvis pain at the same time, I was like, oh my God*". Tessa stated, "*in terms of pain, I don't see a huge difference...sometimes I still need to use a hot bottle to make me feel better. I think...it's impossible if I do yoga for two months and then I would see (change).*"

It was more difficult to see any changes in Margaret's pain levels from the start of the research to her pain levels at the end of the research, as she did not do yoga as consistently as Tessa and Miriam. Margaret was unable to receive any assistance or guidance to doing the yoga poses and exercises correctly, which could ultimately affect how her pain was impacted or not impacted. Margaret stated that she was going through a lot more medical scans and was feeling increased pain throughout the research. She said that this was probably due to the scans rather than the yoga. Despite this, she also said that she did not think the yoga made any difference to her pain: "*I don't think I saw a decrease in pain, but I don't think yoga caused any kind of increase in pain.*"

From looking at the participants' journal entries and analysing their closing interviews, it can be seen that Tessa and Miriam experienced some momentary pain relief during and after attending the yoga class. Miriam said during the closing interview, "*maybe during the yoga sessions, sometimes it was good. Because it got my mind off the pain*". Understanding what Miriam said, the pain relief she experienced could more so be due to the mental aspect of yoga, such as practicing meditation and relaxation techniques, to divert her attention away from the physical pain she was feeling, rather than the physical poses of yoga actually reducing her pain. Tessa also mentioned that sometimes she would feel good during the yoga class or even the following day: "*the following days I felt great*". It seems that Tessa felt mentally great about having done yoga but had not actually had a decrease in pain. Thus, the temporary decrease in pain experienced by both Tessa and Miriam are too inconsistent to establish yoga as an effective form of pain management.

On the other hand, Margaret felt pain during yoga. She had an unfavourable experience with the yoga class and with how the yoga teacher, Samantha, taught the classes. She only attended the yoga classes twice and, in both times, she felt uncomfortable and in pain doing some of the poses. She noted this in her journal and the closing interview, saying: *“I had like, quite a bad shoulder pain afterwards because I felt like she pushed it too far. And it did go away”*, *“and then she still there was one time, she like, pushed my pelvis in a position that then was quite painful because it was kind of straining on where I have a lot of pain. And I did say to her, look, “I can’t go that far””*, and, *“I find that really strange that she would just come in and push”*. Her feeling this pain was directly because of the yoga, although it was more so due to the force of the instructor. As Margaret said, *“I found that when I was doing the classes at home and just pushing it as far as I could...I just enjoyed it more”*. So saying this, Margaret was still able to do the poses without any pain, but it was only when she was pushed past her limit that this caused her to be in more pain, especially in some areas that are activated by the endometriosis (e.g., pelvis).

In terms of positive impact, yoga did make some positive changes in the participants’ lives. The participants recognised that the yoga and research improved to some degree, aspects of their mental health due to confidence and knowledge of their body. For example, practicing yoga and mindfulness, the participants were able to be better the connection to their bodies. This was shown in the example with Miriam, when she acknowledged that the journaling helped her to reflect upon her pain and symptoms whereby, she would purposely try to ignore and separate herself from the pain prior to the research. She said: *“so it was good in terms of putting my feelings down or putting my experience of that day down”*. She also said that the yoga helped her to be more in tune with her body, its abilities and limits: *“being present with our body. Because again, when you’re in pain, like it’s almost like the dissociation from your body causes you pain...”* In addition, Tessa also acknowledged that the yoga and participating in the research helped with her mental health; it helped her to embrace body positivity and the social aspect of the research also decreased her feeling of loneliness. Tessa said: *“so I felt more in common...something that was in common, though it was not a good common”*.

### **Conclusion**

Theme Six essentially covered the answer to the research question: “is yoga an effective form of pain management for endometriosis?” The information gathered from the three participants highlighted that yoga did not create enough significant improvements in the women’s pain levels for it to be established as an effective method for endometriosis-pain relief. Nevertheless, Miriam and Tessa’s improvements in scores in the ‘pain’ domain by the end of the research indicate that

## ENDOMETRIOSIS & YOGA

perception of pain, not sensory experience of pain, had been positively impacted by the yoga. Importantly, the experience of yoga did have benefits for the participants. The overall takeaway is that yoga could not be conclusively determined as an effective form of pain management for endometriosis but may be useful in managing endometriosis in other QOL domains. It should also be noted that factors such as the subjective nature of endometriosis, duration of the research, practice of yoga itself, and other extraneous variables could all play a part in shaping how and how much yoga could impact endometriosis pain. Yoga may be helpful for some and not for others, and also perhaps more-so in the changing pain perception rather than sensorial pain experience.

## Chapter Five: Discussion

The final chapter of this thesis summarises the interpretations, limitations, and implications to the research. I will provide a brief summary of the results obtained in the research. Following this, I will evaluate the strengths and limitations of the research. Thereafter, I will offer implications to increase comprehensive interventions to better both the patient's physiology and also other psychosocial domains impacted by endometriosis-pain in their life. Finally, I will outline the urgency and avenues for future investigation for researchers in Aotearoa, New Zealand.

### Summary

The aim of the research was to analyse how yoga, a practice that focuses beyond physical health and acknowledges mindfulness, can influence a person living with endometriosis and perception and experience of pain, and ultimately affect their self-perceived QOL. Using RTA, six key themes were found within the participants' datasets of their journal entries and their initial and closing interviews: (1) experiencing endometriosis pain, (2) treating endometriosis pain, (3) yoga and QOL, (4) benefits of yoga on the body, (5) benefits of yoga on mental health, and (6) yoga and perception of pain.

Overall, yoga was found not to be effective for pain associated with endometriosis but the participants' perceived QOL were improved in certain mental and physical health domains. Miriam and Tessa exhibited progress in their 'pain' domains, as well as improved scores in the majority of the other domains in the endometriosis health questionnaire at the end of the research, whereas Margaret only displayed an improvement in the 'sexual relationship' domain. Despite Miriam and Tessa displaying improved pain scores, they nevertheless expressed that they did not feel the yoga significantly lowered their pain levels. The improved pain scores on Miriam and Tessa's endometriosis questionnaires could be attributed to improved pain perception, rather than a decrease or improvement in the feeling of sensory pain.

Missmer et al. (2021) suggests that endometriotic patients could have a lowered perception of their QOL due to the negative implications of endometriosis and pain on their goals and expectations for the domains, as well as their lives. This idea was somewhat supported through the findings obtained in this research as the participants had showed higher self-perceived QOL by the end of the research in most of the domains. This was applicable to the three participants who completed the research, Miriam, Tessa, and Margaret. For the domain of 'pain' Margaret had no change in scores and Miriam and Tessa showed improved scores by the end of the research. For the domain of 'control and powerlessness' Margaret had no change in scores and Miriam and Tessa

## ENDOMETRIOSIS & YOGA

showed improved scores by the end of the research. For the domain of ‘emotional wellbeing’ Miriam and Tessa showed improved scores by the end of the research whereas Margaret’s score had worsened (by 10 points) by the end of the research. For the domain of ‘self-image’ Tessa and Margaret showed no change in scores by the end of the research, whereas Miriam’s score had worsened by the end of the research (by 8 points). For the last domain, ‘sexual relationship’, this was not applicable to Tessa so she did not answer questions to this domain, whereas Miriam and Margaret showed improvements in their scores by the end of the research. Miriam and Tessa’s overall QOL scores improved but Margaret’s score did not improve but lowered slightly from overall score of 41.3 to 40.8.

The qualitative data added a level of richness to the data, highlighting the complexity of QOL for women with endometriosis and their pain perception. Listening to the participants who lived through the experience is of the utmost importance to comprehend if and how the yoga affected their pain and endometriosis, as perception and experience of pain is influenced by other non-somatic causes such as psychological, emotional and social components (Smrdu, 2022). The participants all highlighted that yoga had some positive benefits on domains in their lives. They described yoga as having been beneficial for their mental health, emotional wellbeing, social support and fitness. Nevertheless, this research also found that yoga was beneficial to biopsychosocial domains aside from pain, an aspect of the findings which aligned with relevant studies within this research topic; Goncalves et al. (2016) and Goncalves et al. (2017). This finding from my research was also comparable to that of studies assessing endometriosis and mind-body interventions. The studies done by Kold et al. (2012) and Hansen et al. (2017) found that during a six-year follow-up, mindfulness techniques were helpful in alleviating participants’ endometriosis pain and had created lasting positive effects in multiple domains in their EHP-30 scores, indicating improved QOL. My findings relate to these studies as two of the participants also experienced improved QOL which was reflected in their scores in the endometriosis health questionnaires in multiple domains, as well as explicitly sharing these improvements during their closing interviews.

Despite some positive effects, the participants expressed during their closing interviews that the yoga did not substantially improve their pain. Whilst pain can be considered a physiological sensation caused by somatic processes (Smrdu, 2022), how pain is mentally and emotionally perceived by the individual can also influence their experience and how they physically feel the pain (Timotin et al., 2023; Craig & MacKenzie, 2021). This might help explain why my research differs to those of Kold et al.’s (2012) and Hansen et al.’s (2017) who found that mindfulness was effective in controlling pelvic pain. Whereas in my study, whilst Miriam and Tessa described a

## ENDOMETRIOSIS & YOGA

decrease in pain a few times after the yoga class and their scores in the 'pain' domain did improve at the end of the research, they did not regularly and consistently feel their pain get better after doing yoga. Thus, the results highlighted the subjectivity of endometriosis and pain which is supported by the current literature (Craig & MacKenzie, 2021; Triolo et al., 2013).

Studies assessing endometriosis pain management is sparse, and studies looking at yoga specifically as pain management for endometriosis is even more limited. The findings from this research have some contrasts to the most relevant articles. Two studies in particular by Goncalves et al. (2016) and Goncalves et al. (2017) were of relevance to this research topic as they evaluated yoga as pain management for endometriosis. The results of these studies found that yoga was effective in controlling endometriosis-associated pain and helped in improving QOL in endometriotic women (Goncalves et al., 2016; Goncalves et al., 2017). The discrepancy then between the findings of my research and those of these studies may be due to many factors, stemming from the characteristics of the sample, recruitment and selection, and interpretation of data. For example, my study and the study by Goncalves et al. (2016) both instructed participants to practice Hatha yoga for eight weeks, fill in daily pain scales, and complete the pain scales before and after yoga on the days they had yoga. Our studies shared a limitation in that no long-term follow-up was conducted with the participants. I also conducted closing interviews with the participants to get a better understanding of their experiences, just as Goncalves et al. (2017) did. The yoga sessions in the Goncalves et al. (2016) study was held for two hours, twice a week, whereas in my study they were only held for one hour twice a week. The study by Goncalves et al. (2016) also made sure that the same poses and exercises were conducted in each yoga class, allocating set times for each exercise, whereas the yoga classes taught in my research varied in exercises each week, with only some repetition of exercises and the sun salutation as a constant exercise that was practiced in each class. Goncalves et al. (2016) also had forty participants and Goncalves et al. (2017) had fifteen, and having a higher number of participants would impact the average pain scales. These slight differences could be contributing to the different findings.

My study and Goncalves et al.'s (2016) study both recruited endometriotic women who experienced a significant amount of pain regularly. Goncalves et al. (2016) recruited women who scored 4< on a visual analogue scale (VAS), and I recruited women who rated their pain as being at least 'moderate', sharing their pain verbally to me over-the-phone. By only verbally rating their pain levels to me and not using a VAS scale (visual scale) such as Goncalves et al. (2016), this could be a major determinant as to why my results were not alike to Goncalves et al.'s (2016). It could be argued that if they had a visualisation to rate their pain, this could have affected their

rating (e.g., seeing a scale from 0-100 could make them more accurately rate their pain, compared to only categorising their pain as within the constraints of ‘low’, ‘moderate’ or ‘high’, or anywhere in-between these).

In summary, the findings of my research signified that yoga was beneficial for the participants in many aspects and domains including physical health (fitness), psychological wellbeing, and social support. Yoga, however, was not effective in significantly reducing the physical feeling of pain caused by endometriosis.

### *QOL and the Complexities of Living with Endometriosis*

Theoretical perspectives such as that of the biopsychosocial approach recognise the interconnected roles that physiological, psychological and social factors have in influencing one’s perception and thus experience of pain (Bever et al., 2016), as well as how pain can have afflictions on these domains (Smrdu, 2022). All of these play a part in how the individual experiences pain and how the individual understands pain as impacting domains in their lives, affecting their view on themselves, the world and their perception of their QOL. Yoga is a practice which combines physical exercise and mindfulness, and previous studies have supported its efficacy in reducing pain in chronic pain illnesses such as multiple sclerosis (Doulatabad et al., 2013). This research purposely analysed yoga as pain management for endometriosis because it is a practice which understands wellbeing as more than just physical health, valuing the integration of the mind, body and spirit to achieve a balanced relationship between psychological and physical health (Doulatabad et al., 2013; Mikocka-Walus et al., 2021). Yoga fathoms the importance and interconnectedness between various domains in an individual’s life in shaping one’s perceived QOL, and its practices combine physical exercise and mind-body awareness, viewing overall wellbeing as a balanced relationship between the mind, body and spirit (Doulatabad et al., 2013; Holtzman & Beggs, 2013).

In the current literature, QOL is defined as the subjective perception that an individual has on their life (WHO, 2023b). Various facets in an individual’s life are evaluated, such as their personal health (physical, mental and spiritual), interpersonal relationships, autonomy, and financial status, in terms of how their current standing in such domains compare to the goals and expectations they have of themselves in those domains, ultimately influencing their perceived QOL (WHO, 2023b). The complexities of living with endometriosis involve living in and managing pain which impacts many domains of life (Bień et al., 2020). There is consistent research pointing to how endometriosis impacts all of the domains in the patient’s life, ultimately shaping their perception of

their QOL (Bień et al., 2020). The outcomes obtained from my research provide further support for this. This is indication that pain filters through multifaceted domains in an endometriotic woman's life and as domains are affected, so is their perceived QOL (Bień et al., 2020). These results can be evaluated as showing two possibilities: 1) if pain is improved, that means the domains are less adversely impacted, shaping the individual to have a higher self-perceived QOL; 2) as pain and the other domains are interdependent of each other for wellbeing, it can also be said that if the other domains improve, perception of pain may also improve, shaping the individual to have a higher self-perceived QOL. This is in line with the beliefs of the biopsychosocial approach in that biological, psychological and social domains are interconnected to create one's subjective experience of endometriosis and pain (Bevers et al., 2016; Kashi et al., 2018). This also shows how valuable it is to acknowledge QOL in understanding endometriosis and evaluating appropriate methods of treatment and management.

Various domains in an endometriotic woman's life are undoubtedly impacted by endometriosis, but it is difficult to determine which and all of the domains are affected, as these differ across each woman and their values and circumstances. For example, infertility is a symptom and effect of endometriosis (Endometriosis New Zealand, 2023) and only one participant, Margaret, had directly experienced the difficulty of starting a family due to her endometriosis and issues with fertility. Going through fertility challenges, Margaret reported that this affected her mental and physical health. From a feminist perspective, this can be seen as a disruption to both her biology and identity, and by Margaret having to go through medical processes to get pregnant, she is trying to readjust patterns of behaviour (Cole et al., 2021). Thus, how Margaret views herself may change in order to accommodate any effects endometriosis has on her life and her relationships (Cole et al., 2021).

### ***Experience, Perception & Memory of Pain***

Pain was one of the domains assessed and the impacts of endometriosis on pain are understood through the participants' self-evaluations (Oxford University Innovation, 2016). Pain can be described as the subjective physiological or emotional experience of having an unpleasant feeling such as something hurting, caused by signalling from the brain of potential or actual tissue damage (British Pain Society, 2023; Timotin et al. 2023). Alongside this definition, the biopsychosocial approach understands pain to be a combination of physiological, psychological and social components and that these elements are interdependent of each other and influence the individual's experience of pain and therefore also shape their perception of their pain experience (Smrdu, 2022). While my participants perceived yoga to be ineffective in reducing their pain, their

overall QOL and 'pain' scores improved so it could be debated this finding shows how the sensory aspect of pain did not decrease but the participants' perceptions or thoughts around their pain changed.

The memory of pain can also be understood as falling under the realm of a biopsychosocial aspect that influences pain experience and perception. Memories of emotional experiences such as pain can be bias as they are often shaped by the individual's recollection of the peak intensity of emotion they felt and people may be susceptible to remembering more of their worst (emotional and sensory) experiences, leading them to base their memory off of a time/s when they felt the most pain (Urban et al., 2019). This disconnect was evident in how Miriam and Tessa reported that yoga was ineffective in reducing their pain yet the scores on their endometriosis questionnaire showed improvements in the 'pain' domain. By saying that they did not believe the yoga to be beneficial in reducing their endometriosis pain, they may be reflecting on their progress in the research to their memory of 'usual' pain and comparing to the expectations and goals they had going into the research. Memories of past experiences guide future responses, and memories of past feelings can unknowingly be reconstructed and partial to one's present goals and evaluations of past events (Urban et al., 2019). Reflecting on this, perhaps the participants may have had high expectations of reducing their pain when they signed up to the research, and when their progress did not go as they hoped, this made them perceive the yoga to be lower in efficacy and believe their pain had not improved.

From an enactivist approach, how the individual makes sense of an experience is shaped through their body's interaction with the environment and how the mind cognitively perceives the experience (De Haan, 2021). Understanding this perspective, the participants' perceptions of pain prior to starting the research can be said to have been shaped by how they made sense of their physiological sensory experience of pain. The meanings they attached to past experiences of pain and their self-perceptions of pain may have been shaped over a long period of time, throughout their ongoing endometriosis journeys and even since before their diagnosis. Thus, participating in a short research and practicing yoga for only two months may not have been sufficient enough to alter their perceptions of their pain, as the memories of pain they hold are already deeply imprinted in their minds. The complexity of understanding pain, pain experience, pain perception and the memory of pain are all factors which need to be taken into consideration in this research and any future studies on how they all affect the understanding of the true impacts of endometriosis and pain on an individual.

### **Strengths & Limitations**

Despite the fact that the findings of this research have provided support for the consideration and association of QOL when discussing endometriosis and pain, just like all studies, this research comes both with its strengths and limitations. The main limitation was the sample size, only comprising of five participants, two of whom withdrew prior to the implementation of yoga in the research. A larger sample size can be argued as more ideal so as to be more representative of the population of endometriotic women in Aotearoa and thus provide more accurate results (Andrade, 2020), particularly if objective measures of pain are the outcome measure of the study. Also, the participant group only consisted of women who lived on Auckland's North Shore because I had only advertised for participants on North Shore community pages on Facebook. The location of the yoga classes was also held on the North Shore to increase convenience for the participants and thus increase likelihood to participate. Thus, the sample was low in diversity for various attributes such as socioeconomic status, stage of endometriosis, age and ethnicity. This was a clear limitation because as endometriosis affects 1 in 10 Kiwi women (Endometriosis New Zealand, 2023), the characteristics of the participant group were not diverse enough to represent those of the wider population of endometriotic women in New Zealand, decreasing the generalisability of the findings of this research (Subedi, 2021). Conducting a qualitative study with the understanding that endometriosis and pain are subjective notions, this research focused on gaining knowledge and exploring these phenomena rather than generalising the findings (Subedi, 2021). In addition, the sampling method could be compared to purposive sampling as I chose participants who fit the parameters of the research question and purpose (i.e., were in pain due to endometriosis) (Tracy, 2020). Purposive sampling can be advantageous to use in qualitative research because it allowed me to grasp a deeper understanding of the phenomena I aimed to, something that may not have been possible had I had a larger sample (Subedi, 2021). Being selective and having a small sample allowed me to gain rich information from the participants which helped me understand each of their individual lived experiences with endometriosis, pain, and the research.

There were no Māori participants involved in this research which is a limitation. Inclusivity of and relatability to Māori need to be taken into consideration to further knowledge on Māori health and increase potential for improvement in Māori health outcomes (NEAC, 2023). Having Māori participants would have allowed for insight to be gained into the similarities and differences of how QOL is viewed amongst endometriotic Māori women, and whether the domains considered for QOL are as applicable to Māori as they were to non-Māori participants in the research. This then leads onto the questioning of the appropriateness and cultural applicability of using the

## ENDOMETRIOSIS & YOGA

endometriosis health questionnaire with Māori participants as the EHP-30 has not been validated with these populations. In particular, family (whānau) and spirituality are not directly assessed through the endometriosis health questionnaire. This implies that the questionnaire itself is not considering pivotal domains which are considerably impacted by the Māori women's endometriosis and pain contributing to wellbeing and QOL (Wyeth et al., 2013). Without including all domains important to Māori wellbeing, the endometriosis health questionnaire used in this research and therefore the EHP-30 (as this influenced the design of the questionnaire used in the research), could be seen as lacking in true cross-cultural validity by not adapting the questionnaire to have appropriate sociocultural context to these participants (Ercikan et al., 2023). A direction for future research would be to find endometriosis health questionnaires assessing QOL which have cultural validity in application to Māori wahine living with endometriosis and that reflect more holistic models such as te whare tapa whā.

A strength of the mixed methods research design is it allowed participants to talk about the QOL domains of family and spirituality terms of how they were affected by endometriosis and pain. Nevertheless, this research and others in the future should be more inclusive of and incorporate different understandings of wellbeing from all women such as Māori, Pasifika and Asian women. These groups make up large populations in New Zealand (Statistics New Zealand, 2018) and hold more holistic and collectivist worldviews (Boon-Nanai et al., 2022) and thus the domains considered for their QOL would have some differences to that of Western individuals. In addition, more research is needed about endometriosis with gender diverse people, people with disability, and different age groups as QOL domains and experiences of endometriosis vary greatly.

Yoga recognises wellbeing as an intertwining of many factors, such as mental, spiritual and physical health (Doulatabad et al., 2013). This is a strength of this research as Māori wellbeing also consider to be comprised of a balanced connection between similar domains, such as mental, spiritual, physical health and social/family support (Mental Health Foundation, 2023). Thus, yoga still values these domains prioritised by Māori by using mindfulness techniques and exercises aimed at improving the balance between the mind, body and soul to achieve holistic wellbeing (Doulatabad et al., 2013). Yoga, has been critiqued for being commercialised, taking it out of the spiritual domains into a capitalist enterprise for a privileged few (Antony, 2018).

The yoga instructor is also important to consider in terms of her influence in the research. Samantha is a qualified yoga instructor, having completed 200 hours of yoga teacher training, but does not teach yoga classes herself. Although Miriam and Tessa had positive feedback about Samantha's ways of teaching the yoga classes, Margaret did not have a positive experience with

## ENDOMETRIOSIS & YOGA

her. While Margaret stopped going to the yoga classes in-person due to work commitments, it should be reflected upon whether Margaret's disapproval of Samantha's teaching style was also a factor which supported her decision to stop attending the yoga classes. How the teacher interacted with the participants is very important to consider. For example, she may not have guided the yoga class with the same sensitivity and communication style as other more experienced yoga teachers might do.

Furthermore, on reflecting on the study design, the endometriosis health questionnaire also had its limitations. The endometriosis questionnaire was created following the contextual design of the EHP-30, with a combination of the domains from both the core and the modular segments of the EHP-30. The questionnaire was made up of the following domains: pain, control and powerlessness, self-image, emotional wellbeing, and sexual relationship. In contrast, the EHP-30 included domains such as pain, control and powerlessness, self-image, emotional wellbeing, and social support (Oxford University Innovation, 2016). I exchanged 'social support' with 'sexual relationship' as a domain in the endometriosis health questionnaire because I thought that this can cover dating and intimate relationships as this is a domain that can be impacted by endometriosis (Teoli & Bhardwaj, 2022). I also used 'sexual relationship' rather than 'social support' because assessing a woman's sexual relationship with her partner, especially if they were trying to conceive, could provide a deeper understanding to the how infertility can also impact the relationships in the woman's life. As the research went on, I discovered that social support, or lack thereof was an important topic and that social support and understanding is vital in living with chronic illness. Thus, having the 'social support' domain then would have been advantageous to include in the endometriosis questionnaire, as once the research concluded, it could be assessed if the participants perceived having more social support since attending the yoga classes and meeting other women living with endometriosis. It could then be evaluated whether improved social support also leads to improved wellbeing (Leggott, 2020). Nevertheless, because this research did not solely rely on quantitative measures, I was still able to attain information from the participants on their feelings and experiences with social support through the interviews.

Finally, the methodology that was used in the research also comes with both strengths and limitations. I used reflexive thematic analysis (RTA), which emphasises on the researcher's active engagement and subjective interpretation of the dataset (Braun & Clarke, 2021). Using RTA meant that my interpretations of the data were made from a combination of my reflection of the data, considerations surrounding what theories state about such data, and utilisation of my knowledge and skills in analysis (Braun & Clarke, 2019). Thus, my personal interpretations and judgment of the

dataset shaped how the final outcomes are construed and understood by others (Finlay, 2021). Notwithstanding, the versatility of RTA was deemed appropriate to use in this research because it required a researcher to be critical, questioning and deeply reflecting upon such rich and qualitative information obtain from the participants. This act of reflexivity encourages subjectivity through the active engagement of the researcher, enhancing the quality of the research through the immense reflexivity and critical thinking of the research towards the data (Joy et al., 2023). Using RTA also allowed for thoughtful engagement from me, the researcher, and it is with the understanding that with such rich qualitative data, the aim is not to interpret findings in order to pursue consensus, but to embrace researcher subjectivity, as qualitative data also emphasises subjectivity.

### **Practical Implications**

From the results, it can be observed that although the physiological sensation of pain was not reduced by the yoga, psychosocial domains had benefitted from the implementation of the practice. Although this research was unable to conclusively find and claim that yoga was beneficial in reducing endometriosis pain, the relevant studies by Goncalves et al. (2016) and Goncalves et al. (2017) which studied the same concepts, yoga and endometriosis, found that yoga was effective in improving physiological pain caused by endometriosis. Kold et al. (2012) and Hansen et al. (2017) studied mindfulness and endometriosis and also found mindfulness to be helpful in improving the feeling of pain caused by endometriosis. All of these studies gained support for the practice of yoga and mindfulness in endometriosis pain management. So, even though my research did not attain similar results, it still bears to reason that further investigation into the realm of non-medical endometriosis pain management, such as mindfulness and yoga, is required and would be beneficial in adding onto the current sparse knowledge in the field.

Next, although not mutually shared by participants, doing the yoga and being part of the research was enjoyable due to a sense of relatability. Two participants who did the yoga (Miriam and Tessa) seemed to lack an aspect of social support from not having people to relate to in their lives with endometriosis, which would have impacted their mental wellbeing and their experiences and perceptions in physiological and psychological pain (Kalfas et al., 2022). Obtaining this knowledge that social support can be beneficial for the wellbeing of endometriotic patients, it is thus highly recommended that more comprehensive forms of pain management for endometriosis are implemented which incorporate working with various people in the women's lives such as their partners, whānau, and endometriosis support groups.

The results accentuate the need to incorporate more comprehensive pain interventions and treatments which take into consideration the concept of QOL so that the biopsychosocial domains which are impacted by endometriosis and pain can also be assessed and targeted for improvement, as they also play a part in the individual's wellbeing (Bevers et al., 2016; Smrdu, 2022). It is proposed that more holistic, multidisciplinary and patient-centred interventions should be applied so that non-physiological domains within the patient's life are also taken into consideration for improvement and their psychological wellbeing and QOL are also prioritised (Van Niekerk et al., 2022). An implication is also aimed towards healthcare practitioners to increase their awareness and knowledge on endometriosis so as to eliminate stigma around the illness, create an environment where women feel safe and listened-to, and reduce the delay in diagnosis for endometriosis. Furthermore, as the domains in each patient's life are impacted to varying extents, subjectivity should also still be prioritised when carrying out interventions and treatments, as no two women living with endometriosis go through the same experience. Lastly, I offer an implication for health care practitioners and researchers to focus on the context of Aotearoa New Zealand and the current lack of resources for assessing QOL in women living with endometriosis. Prior to conducting this research, I was only able to find one study focusing on QOL in Aotearoa which was done by Tewhaiti-Smith et al. (2022). This study utilised a 99-item questionnaire component of the World Endometriosis Research Foundation (WERF) EndoCost tool and had it contextually adapted to a New Zealand demographic to assess the impacts of endometriosis on various life domains associated with QOL (Tewhaiti-Smith, 2022). This study is a step forward in adding onto the current lack of knowledge and awareness in New Zealand concerning endometriosis and QOL. The EHP-30 is the most extensively validated tool across the globe that assesses endometriosis HRQOL (Jia et al., 2012), and so it would be more favourable to utilise a tool such as the EHP-30 that is recognised internationally. The EHP-30 can also be given to assess non-English speaking patients, as it is available in 15 languages and has been evaluated for responsiveness, reliability and validity in linguistic cultural adaptation (Oxford University Innovation, 2016; Verket et al., 2018). In saying this, the EHP-30 is still yet to be culturally adapted for Māori and Pasifika, not only in terms of language, but more importantly in relation to the multifaceted QOL domains.

It is without a doubt that there still exists a large gap within the topic of endometriosis and definitive treatments. Until this gap is closed healthcare practitioners and researchers have the responsibility to continue to explore and discover effective forms of pain management. Current medical treatments and interventions still yield recurrence of pain and other symptoms (Ellis et al., 2022), highlighting the need for more comprehensive methods. The connection between

endometriosis, pain and QOL is evident. Therefore, it is imperative and urged that practitioners understand the person and their experience with endometriosis and pain through a holistic lens, understanding their experience beyond physiology and that their experience is formed through an intertwining of biopsychosocial factors (Bever et al., 2016). They need to take into consideration the impacts endometriosis and pain has caused on the multifaceted domains in the patient's life to understand how their overall wellbeing and QOL has been afflicted, and how improvements in these domains can also contribute to the patient's perception of pain and their QOL. Practices such as yoga which combine physical activity and mindfulness have produced mixed outcomes in terms of its efficacy in reducing pelvic pain caused by endometriosis. Although the research surrounding this topic is still sparse, past evidence from relevant articles (Goncalves et al., 2016; Goncalves et al., 2017) have shown yoga to alleviate endometriosis-associated pain and thus further research regarding this topic is encouraged to add on to the current literature.

### **Conclusion**

This research found that although two out of the three participants who practiced yoga in the research showed improved scores in the domain of 'pain' by the end of the research, they shared explicitly during their closing interviews that they did not regard the yoga as effective in alleviating their overall feeling of pain. This signifies that the improved scores on the 'pain' domain could signify improved pain perception, rather than improved sensory experience of pain. Other domains' scores were also better by the end of the research and their overall QOL scores also progressed suggesting yoga does have a positive impact on pain perception rather than physiological pain. Endometriosis affects the individual beyond physiological pain, with the symptom of pain having negative afflictions on numerous psychosocial domains in the individual's life which influence the individual's perception of their QOL (Kashi et al., 2018). It is also to be noted that these same domains affected by endometriosis and pain are also contributing factors to the individual's wellbeing which also help shape their perception and experience of pain (Smrdu, 2022). In conclusion, the findings of this research indicate that yoga may have improved perception of pain and therefore QOL but there was not enough significant evidence obtained to claim that yoga effectively improved the sensory feeling of pain. There is a clear connection between endometriosis, pain, and QOL but more research is needed for deeper understanding and clarification.

## References

- Aftab, A., & Nielsen, K. (2021). From Engel to enactivism: Contextualizing the biopsychosocial model. *European Journal of Analytic Philosophy*, 17(2), 5-22. <https://doi.org/10.31820/ejap.17.2.3>
- Agarwal, S. K., Antunez-Flores, O., Foster, W. G., Hermes, A., Golshan, S., Soliman, A. M., Arnold, A., & Luna, R. (2021). Real-world characteristics of women with endometriosis-related pain entering a multidisciplinary endometriosis program. *BMC Women's Health*, 21(19), 1-14. <https://doi.org/10.1186/s12905-020-01139-7>
- Alsaawi, A. (2014). A critical review of qualitative interviews. *European Journal of Business and Social Sciences*, 3(4), 149-156. <https://dx.doi.org/10.2139/ssrn.2819536>
- Andrade, C. (2020). Sample size and its importance in research. *Indian Journal of Psychological Medicine*, 42(1), 102-103. [https://doi.org/10.4103%2FIJPSYM.IJPSYM\\_504\\_19](https://doi.org/10.4103%2FIJPSYM.IJPSYM_504_19)
- Antony, M. G. (2018). That's a stretch: Reconstructing, rearticulating, and commodifying yoga. *Frontiers in Communication*, 3(47), 1-12. <https://doi.org/10.3389/fcomm.2018.00047>
- Armour, M., Sinclair, J., Chalmers, K. J., & Smith, C. A. (2019). Self-management strategies amongst Australian women with endometriosis: A national online survey. *BMC Complementary Medicine and Therapies*, 19(1), 1-8. <https://doi.org/10.1186/s12906-019-2431-x>
- Arnold, J., Vercellino, G. F., Chiantera, V., Schneider, A., Mechsner, S., & Barcena de Arellano, M. L. (2013). Neuroimmunomodulatory alterations in non-lesional peritoneum close to peritoneal endometriosis. *Neuroimmunomodulation*, 20(1), 9-18. <https://doi.org/10.1159/000342163>
- Banerjee, M., Cavanagh, K., & Strauss, C. (2017). Barriers to mindfulness: A path analytic model exploring the role of rumination and worry in predicting psychological and physical engagement in an online mindfulness-based intervention. *Mindfulness*, 9, 980-992. <https://link.springer.com/article/10.1007/s12671-017-0837-4>
- Bendelow, G. (2013). Chronic pain patients and the biomedical model of pain. *Virtual Mentor*, 15(5), 455-459. <http://dx.doi.org/10.1001/virtualmentor.2013.15.5.msoc1-1305>
- Berker, B., & Seval, M. (2015). Problems with the diagnosis of endometriosis. *Women's Health*, 11(5), 597-601. <https://doi.org/10.2217/whe.15.44>
- Best Practice Advocacy Centre New Zealand. (2021). *Endometriosis: Diagnosis and management*. <https://bpac.org.nz/2021/endometriosis.aspx>
- Better Evaluation. (2022). *Line graph*. <https://www.betterevaluation.org/methods-approaches/methods/line-graph>

- Beyers, K., Watts, L., Kishino, N. D., & Gatchel, R. J. (2016). The biopsychosocial model of the assessment, prevention, and treatment of chronic pain. *US Neurology*, *12*(2), 98-104. <https://doi.org/10.17925/USN.2016.12.02.98>
- Bień, A., Rzonca, E., Zarajczyk, M., Wilkosz, K., Wdowiak, A., & Iwanowicz-Palus, G. (2020). Quality of life in women with endometriosis: A cross-sectional survey. *Quality of Life Research*, *29*, 2669-2677. <https://doi.org/10.1007/s11136-020-02515-4>
- Bischoff, F., & Simpson, J. L. (2004). Genetics of endometriosis: Heritability and candidate genes. *Best Practice & Research Clinical Obstetrics and Gynaecology*, *18*(2), 219-232. <https://doi-org.ezproxy.massey.ac.nz/10.1016/j.bpobgyn.2004.01.004>
- Boon-Nanai, J., Thaggard, S., & Montayre, J. (2022). 'I just want to be a grandmother, not a caregiver for their kids'. Perceptions of childminding among Pacific grandparents living in Aotearoa New Zealand. *Health and Social Care in the Community*, *30*(4), 1599-1607. <https://doi.org/10.1111/hsc.13492>
- Bourdel, N., Alves, J., Pickering, G., Ramilo, I., Roman, H., & Canis, M. (2015). Systematic review of endometriosis pain assessment: How to choose a scale? *Human Reproduction Update*, *21*(1), 136-152. <https://doi.org/10.1093/humupd/dmu046>
- Bourdel, N., Chauvet, P., Billone, V., Douridas, G., Fauconnier, A., Gerbaud, L., & Canis, M. (2019). Systematic review of quality of life measures in patients with endometriosis. *PLoS ONE*, *14*(1), 1-32. <https://doi.org/10.1371/journal.pone.0208464>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE Publications.
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597. <https://doi.org/10.1080/2159676X.2019.1628806>
- Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328-352. <https://doi.org/10.1080/14780887.2020.1769238>
- Braun, V., Clarke, V., & Hayfield, N. (2022). 'A starting point for your journey, not a map': Nikki Hayfield in conversation with Virginia Braun and Victoria Clarke about thematic analysis. *Qualitative Research in Psychology*, *19*(2), 424-445. <https://doi.org/10.1080/14780887.2019.1670765>
- British Pain Society. (2023). *What is pain?* <https://www.britishpainsociety.org/about/what-is-pain/>
- Bush, D., Brick, E., East, M. C., & Johnson, N. (2017). Endometriosis education in schools: A New Zealand model examining the impact of an education program in schools on early recognition of symptoms suggesting endometriosis. *Australian & New Zealand Journal of Obstetrics and Gynaecology*, *57*, 452-457.

- Byrne, D. (2022). A worked example of Braun & Clarke’s approach to reflexive thematic analysis. *Quality & Quantity*, 56, 1391-1412. <https://doi.org/10.1007/s11135-021-01182-y>
- Carney, J. (2020). Thinking avant la lettre: A review of 4E cognition. *Evolutionary Studies in Imaginative Culture*, 4(1), 77-90. <https://doi.org/10.26613/2Fesic%2F4.1.172>
- Chimenti, R., Frey-Law, L., & Sluka, K. (2023). *A mechanistic approach to pain management: Applying the biopsychosocial model to physical therapy*. International Association for the Study of Pain. <https://www.iasp-pain.org/publications/relief-news/article/mechanistic-pain-management-biopsychosocial-model/>
- Cole, J. M., Grogan, S., & Turley, E. (2021). “The most lonely condition I can imagine”: Psychosocial impacts of endometriosis on women’s identity. *Feminism & Psychology*, 31(2), 171-191. <http://dx.doi.org/10.1177/0959353520930602>
- Coninx, S., & Stilwell, P. (2021). Pain and the field of affordances: An enactive approach to acute and chronic pain. *Synthese*, 199, 7835-7853. <https://doi.org/10.1007/s11229-021-03142-3>
- Craig, K. D., & MacKenzie, N. E. (2021). What is pain: Are cognitive and social features core components? *Paediatric & Neonatal Pain*, 3, 106-118. <https://doi.org/10.1002/pne2.12046>
- Culley, L., Hudson, N., Mitchell, H., Law, C., Denny, E., & Raine-Fenning, N. (2013a). *Endometriosis: Improving the wellbeing of couples: Summary report and recommendations*. Pelvic Pain Support Network. <https://www.pelvicpain.org.uk/wp-content/uploads/2018/07/Endopart-study-summary-report-and-recommendations.pdf>
- Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgarten, M., & Raine-Fenning, N. (2013b). The social and psychological impact of endometriosis on women’s lives: A critical narrative review. *Human Reproduction Update*, 19(6), 625-639. <https://doi.org/10.1093/humupd/dmt027>
- De Haan, S. (2021). Bio-psycho-social interaction: An enactive perspective. *International Review of Psychiatry*, 33(5), 471-477. <https://doi.org/10.1080/09540261.2020.1830753>
- Di Paolo, E. & Thompson, E. (2014). The enactive approach. In L. Shapiro (Ed.), *The Routledge handbook of embodied cognition* (pp. 68–78). Routledge.
- Dinsdale, N., Nepomanschy, P., & Crespi, B. (2021). The evolutionary biology of endometriosis. *Evolution, Medicine, and Public Health*, 9(1), 174-191. <https://doi.org/10.1093/emph/eoab008>
- DiVasta, A. D., Vitonis, A. F., Laufer, M. R., & Missmer, S. A. (2018). Spectrum of symptoms in women diagnosed with endometriosis during adolescence vs adulthood. *American Journal of Obstetrics & Gynecology*, 218(3), 324.e1-324.e11. <https://doi.org/10.1016/j.ajog.2017.12.007>
- Doulatabad, S. N., Nooreyan, K., Doulatabad, A. N., & Noubandegani, Z. M. (2013). The effects of pranayama, hatha and raja yoga on physical pain and the quality of life of women with

multiple sclerosis. *African Journal of Traditional, Complementary and Alternative Medicines*, *10*(1), 49-52. <http://dx.doi.org/10.4314/ajtcam.v10i1.8>

Eccleston, C. (2011). *A normal psychology of chronic pain*. The British Psychological Society. <https://www.bps.org.uk/psychologist/normal-psychology-chronic-pain>

Ellis, K., Munro, D., & Wood, R. (2022). The experiences of endometriosis patients with diagnosis and treatments in New Zealand. *Frontiers in Global Women's Health*, *3*, 1-20. <https://doi.org/10.3389/fgwh.2022.991045>

Ellis, K., Munro, D., & Wood, R. (2023). Dismissal informs the priorities of endometriosis in New Zealand. *Frontiers in Medicine*, *10*, 1-13. <https://doi.org/10.3389/fmed.2023.1185769>

Endometriosis New Zealand. (2023). *Endo information*. <https://nzendo.org.nz/endo-information/>

Ensari, I., Lipsky-Gorman, S., Horan, E. N., Bakken, S., & Elhadad, N. (2022). Associations between physical exercise patterns and pain symptoms in individuals with endometriosis: A cross-sectional mHealth-based investigation. *BMJ Open*, *12*(7), 1-12. <https://doi.org/10.1136/bmjopen-2021-059280>

Ercikan, K., Por, H-H., & Guo, H. (2023). Cross-cultural validity and comparability in assessments of complex constructs. In N. Foster & M. Piacentini (Eds.), *Innovating Assessments to Measure and Support Complex Skills*, (pp. 190-210). OECD Publishing. <https://www.oecd-ilibrary.org/sites/91f3d034-en/index.html?itemId=/content/component/91f3d034-en>

European Pain Federation. (2022). *What is the biopsychosocial model of pain?* <https://europeanpainfederation.eu/what-is-the-bio-psycho-social-model-of-pain/>

Evans, S., Fernandez, S., Olive, L., Payne, L. A., & Mikocka-Walus, A. (2019). Psychological and mind-body interventions for endometriosis: A systematic review. *Journal of Psychosomatic Research*, *124*, 1-11. <https://doi.org/10.1016/j.jpsychores.2019.109756>

Farias, M., & Wikholm, C. (2016). Has the science of mindfulness lost its mind? *BJPsych Bulletin*, *40*(6), 329-332. <https://doi.org/10.1192%2Fpb.bp.116.053686>

Fauconnier, A., Staraci, S., Darai, E., Descamps, P., Nisolle, M., Panel, P., Roman, H., & Boukdedid, R. (2018). A self-administered questionnaire to measure the painful symptoms of endometriosis: Results of a modified DELPHI survey of patients and physicians. *Journal of Gynecology, Obstetrics and Human Reproduction*, *47*, 69-79. <https://doi.org/10.1016/j.jogoh.2017.11.003>

Fedele, L., Parazzini, F., Bianchi, S., Arcaini, L., & Candiani, G. B. (1990). Stage and localization of pelvic endometriosis and pain. *Fertility and Sterility*, *53*(1), 155-158. [https://doi.org/10.1016/S0015-0282\(16\)53232-4](https://doi.org/10.1016/S0015-0282(16)53232-4)

Finlay, L. (2021). Thematic analysis: The 'good', the 'bad' and the 'ugly'. *European Journal for Qualitative Research in Psychotherapy*, *11*, 103-116. <https://ejqrp.org/index.php/ejqrp/article/view/136/93>

- Foster, W. G., & Leonardi, M. (2021). Endometriosis- novel approaches and controversies debated. *Reproduction & Fertility*, 2(4), 39-41. <https://doi.org/10.1530%2FRAF-21-0097>
- Goncalves, R. B., Coletta, R. D., Silverio, K. G., Benevides, L., Casati, M. Z., Da Silva, J. S., & Nociti Jr. F. H. (2011). Impact of smoking on inflammation: Overview of molecular mechanisms. *Inflammation Research*, 60, 409-424. <https://doi.org/10.1007/s00011-011-0308-7>
- Goncalves, A. V., Makuch, M. Y., Setubal, M. S., Barros, N. F., & Bahamondes, L. (2016). A qualitative study on the practice of yoga for women with pain-associated endometriosis. *The Journal of Alternative and Complementary Medicine*, 22(12), 977-982.
- Goncalves, A. V., Barros, N. F., & Bahamondes, L. (2017). The practice of Hatha yoga for the treatment of pain associated with endometriosis. *The Journal of Alternative and Complementary Medicine*, 23(1), 45-52. <https://doi.org/10.1089/acm2015.0343>
- Gonzalez-Echevarria, A. M., Rosario, E., Acevedo, S., & Flores, I. (2019). Impact of coping strategies on quality of life of adolescents and young women with endometriosis. *Journal of Psychosomatic Obstetrics & Gynecology*, 40(2), 138-145. <https://doi.org/10.1080/0167482X.2018.1450384>
- Gordon, H. G., Mooney, S. S., Conroy, I. C., & Grover, S. R. (2022). When pain is not the whole story: Presenting symptoms of women with endometriosis. *Australian & New Zealand Journal of Obstetrics & Gynaecology*, 62, 434-438. <https://doi.org/10.1111/ajo.13482>
- Grogan, S., Turley, E., & Cole, J. (2018). ‘So many women suffer in silence’: A thematic analysis of women’s written accounts of coping with endometriosis. *Psychology & Health*, 33(11), 1364-1378. <https://doi.org/10.1080/08870446.2018.1496252>
- Grundström, H., Kjølhede, P., Berterö, C., & Alehagen, S. (2016). “A challenge”- Healthcare professionals’ experiences when meeting with symptoms that might indicate endometriosis. *Sexual and Reproductive Healthcare*, 7, 65-69. <http://dx.doi.org/10.1016/j.srhc.2015.11.003>
- Guidone, H. C. (2020). The womb wanders not: Enhancing endometriosis education in a culture of menstrual misinformation. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling & T-A. Roberts (Eds.), *The Palgrave Handbook of Critical Menstruation Studies*, (pp. 269-286). Springer Nature Singapore. <https://doi.org/10.1007/978-981-15-0614-7>
- Gupta, J., Cardoso, L. F., Harris, C. S., Dance, A. D., Seckin, T., Baker, N., & Ferguson, Y. O. (2018). How do adolescent girls and boys perceive symptoms suggestive of endometriosis among their peers? Findings from focus group discussions in New York. *BMJ Open*, 8(6), 1-11. <https://doi.org/10.1136%2Fbmjopen-2017-020657>
- Haigh, F., Kemp, L., Bazeley, P., & Haigh, N. (2019). Developing a critical realist informed framework to explain how the human rights and social determinants of health relationship work. *BMC Public Health*, 19, 1-12. <https://doi.org/10.1186/s12889-019-7760-7>

- Hansen, K. E., Kesmodel, U. S., Kold, M., & Forman, A. (2017). Long-term effects of mindfulness-based psychological intervention for coping with pain in endometriosis: A six-year follow-up on a pilot study. *Nordic Psychology*, *69*, 100-109.  
<https://doi.org/10.1080/19012276.2016.1181562>
- Hansen, K. E., Lambek, R., Røssaak, K., Egekvist, A. G., Marschall, H., Forman, A., & Kesmodel, U. S. (2021). Health-related quality of life in women with endometriosis: Psychometric validation of the endometriosis health profile 30 questionnaire using confirmatory factor analysis. *Human Reproduction Open*, *2022*(1), 1-11.  
<https://doi.org/10.1093/hropen/hoab042>
- Haryono, I. R., Sudarman, J. P., Prastowo, N. A., & Lilis, L. (2023). The effect of Hatha yoga on pain intensity in severe primary dysmenorrhea among students: A randomized controlled trial. *Indonesian Journal of Nursing and Midwifery*, *11*(1), 95-105.  
<https://ejournal.almaata.ac.id/index.php/JNKI/article/view/3052/pdf10>
- Health Navigator New Zealand. (2022). *Endometriosis (kōpū whakatupu pūtautau)*.  
<https://www.healthnavigator.org.nz/health-a-z/e/endometriosis/>
- Hirata, T., Koga, K., & Osuga, Y. (2020). Extra-pelvic endometriosis: A review. *Reproductive Medicine and Biology*, *19*(4), 323-333. <https://doi.org/10.1002%2Frm2.12340>
- Holtzman, S., & Beggs, R. T. (2013). Yoga for chronic low back pain: A meta-analysis of randomized controlled trials. *Rain Research & Management*, *18*(5), 267-272.  
<https://doi.org/10.1155/2013/105919>
- Hoss, L., & Hynes, K. C. (2022). A both-and approach: An application of narrative interventions from a modern perspective. *Contemporary Family Therapy*, *44*, 305-311.  
<https://doi.org/10.1007/s10591-021-09582-w>
- Hudson, N. (2022). The missed disease? Endometriosis as an example of ‘undone science’. *Reproductive BioMedicine and Society Online*, *14*, 20-27.  
<https://doi.org/10.1016/j.rbms.2021.07.003>
- Insight Endometriosis (n.d.a). *Diagnosing endometriosis in NZ information guide*.  
[https://www.insightendometriosis.org.nz/files/ugd/834000\\_66ec9847a1d549f595a0101fcc0a7c05.pdf](https://www.insightendometriosis.org.nz/files/ugd/834000_66ec9847a1d549f595a0101fcc0a7c05.pdf)
- Insight Endometriosis. (n.d.b). *Empowering people with information and support*.  
<https://www.insightendometriosis.org.nz>
- Insight Endometriosis. (n.d.c). *Endometriosis information guide*.  
[https://www.insightendometriosis.org.nz/files/ugd/834000\\_cb4d72c12fd94f3e9d6592b21b551ddd.pdf](https://www.insightendometriosis.org.nz/files/ugd/834000_cb4d72c12fd94f3e9d6592b21b551ddd.pdf)
- Institute for Quality and Efficiency in Health Care. (2021). *Treatment options for endometriosis*.  
<https://www.informedhealth.org/treatment-options-for-endometriosis.html>
- International Association for the Study of Pain. (2021). *Terminology*. <https://www.iasp-pain.org/resources/terminology/>

- Itani, R., Soubra, L., Karout, S., Rahme, D., Karout, L., & Khojah, H. M. J. (2022). Primary dysmenorrhea: Pathophysiology, diagnosis, and treatment updates. *Korean Journal of Family Medicine*, 43(2), 101-108. <https://doi.org/10.4082%2Fkjm.21.0103>
- Janssen, E. B., Rijkers, A. C., Hoppenbrouwers, K., Meuleman, C., & D'Hooghe, T. M. (2013). Prevalence of endometriosis diagnosed by laparoscopy in adolescents with dysmenorrhea or chronic pelvic pain: A systematic review. *Human Reproduction Update*, 19(5), 570-582. <https://doi.org/10.1093/humupd/dmt016>
- Jia, S-Z., Leng, J-H., Shi, J-H., Sun, P-R., & Lang, J-H. (2012). Health-related quality of life in women with endometriosis: A systematic review. *Journal of Ovarian Research*, 5(29), 1-9. <https://ovarianresearch.biomedcentral.com/articles/10.1186/1757-2215-5-29>
- Jo, J., & Lee, S. H. (2018). Heat therapy for primary dysmenorrhea: A systematic review and meta-analysis of its effects on pain relief and quality of life. *Scientific Reports*, 8(16252), 1-8. <https://doi.org/10.1038/s41598-018-34303-z>
- Joy, E., Braun, V., & Clarke, V. (2023). Doing reflexive thematic analysis: A reflexive account. In F. Meyer & K. Meissel (Eds.), *Research methods for education and the social disciplines in Aotearoa New Zealand*, (pp. 155-168). NZCER Press.
- Kalfas, M., Chisari, C., & Windgassen, S. (2021). Psychosocial factors associated with pain and health-related quality of life in endometriosis: A systematic review. *European Journal of Pain*, 26(9), 1827-1848. <https://doi.org/10.1002/ejp.2006>
- Karnilowicz, W., Ali, L., & Phillimore, J. (2014). Community research within a social constructionist epistemology: Implications for “scientific rigor”. *Community Development*, 45(4), 353-367. <https://doi.org/10.1080/15575330.2014.936479>
- Kashi, A. M., Moradi, Y., Chaichian, S., Najmi, Z., Mansori, K., Salehin, F., Rastgar, A., & Khateri, S. (2018). Application of the World Health Organisation quality of life instrument, short form (WHOQOL-BREF) to patients with endometriosis. *Obstetrics & Gynecology Science*, 61(5), 598-604. <https://doi.org/10.3390/jcm12124056>
- Kempner, J. (2014). *Not tonight*. University of Chicago Press. <https://doi.org/10.7208/9780226179292>
- Keosaian, J. E., Lemaster, C. M., Dresner, D., Godersky, M. E., Paris, R., Sherman, K. J., & Saper, R. B. (2016). “We’re all in this together”: A qualitative study of predominantly low income minority participants in a yoga trial for chronic low back pain. *Complementary Therapies in Medicine*, 24, 34-39. <http://dx.doi.org/10.1016/j.ctim.2015.11.007>
- Kold, M., Hansen, T., Vedsted-Hansen, H., & Forman, A. (2012). Mindfulness-based psychological intervention for coping with pain in endometriosis. *Nordic Psychology*, 64(1), 2-16. <https://doi.org/10.1080/19012276.2012.693727>
- Koopmans, E., & Schiller, C. (2022). Understanding causation in healthcare: An introduction to critical realism. *Qualitative Health Research*, 32(8-9), 1207-1214. <https://doi.org/10.1177/10497323221105737>

- Kotowska, M., Urbaniak, J., Falecki, W. J., Lazarewicz, P., Masiak, M., & Szymusik, I. (2021). Awareness of endometriosis symptoms- A cross sectional survey among Polish women. *Environmental Research and Public Health*, 18(18), 1-7. <https://doi.org/10.3390/ijerph18189919>
- Kuan, K. K. W., Gibson, D. A., Whitaker, L. H. R., & Horne, A. W. (2021). Menstruation dysregulation and endometriosis development. *Frontiers in Reproductive Health*, 3, 1-8. <https://doi.org/10.3389/frph.2021.756704>
- Kukihara, H., Yamawaki, N., Ando, M., Nishio, M., Koga, K., Kimura, H., & Mtasuda, T. (2020). Effects of exercise and mindfulness-based yoga programs on promotion of resilience and mental health of older adults in Japan: A randomized-controlled trial. *Psychology*, 11(2), 285-298. <https://doi.org/10.4236/psych.2020.112018>
- Lagana, A. S., Garzon, S., Gotte, M., Vigano, P., Franchi, M., Ghezzi, F., & Martin, D. C. (2019). The pathogenesis of endometriosis: Molecular and cell biology insights. *International Journal of Molecular Sciences*, 20(22), 1-42. <https://doi.org/10.3390/ijms20225615>
- Lee, S-Y., Koo, Y-J., & Lee, D-H. (2021). Classification of endometriosis. *Yeungnam University Journal of Medicine*, 38(1), 10-18. <https://doi.org/10.12701%2Fyujm.2020.00444>
- Leggott, M. (2020). *You are not a burden: Social support + endometriosis*. <https://endometriosisnetwork.com/blog/you-are-not-a-burden-social-support-endometriosis>
- Lena, F., Pappaccogli, M., Santilli, M., Torre, M., Modugno, N., & Perrotta, A. (2022). How does semantic pain and words condition pain perception? A short communication. *Neurological Sciences*, 43, 691-696. <https://doi.org/10.1007/s10072-021-05577-5>
- Li, L., Lou, K., Chu, A., O'Brien, E., Molina, A., & Riley, K. (2023). Complementary therapy for endometriosis related pelvic pain. *Journal of Endometriosis and Pelvic Pain Disorders*, 15(1), 34-43. <https://doi.org/10.1177/22840265231159704>
- Lisboa, J. L. C. (2018). Qualitative research: Epistemological, theoretical and methodological foundations. *Vivat Academia, Revista de Comunicación*, 144, 69-76. <https://doi.org/10.15178/va.2018.144.69-76>
- Long, A. J., Kaur, P., Lukey, A., Allaire, C., Kwon, J. S., Talhouk, A., Yong, P. J., & Hanley, G. E. (2023). Reoperation and pain-related outcomes after hysterectomy for endometriosis by oophorectomy status. *American Journal of Obstetrics and Gynecology*, 228(57), e1-e18. <https://doi.org/10.1016/j.ajog.2022.08.044>
- Lynn Institute. (2023). *Dealing with research participant bias in clinical studies: The practical approach*. <https://lhsi.net/research-participant-bias-in-clinical-studies/>
- Maddern, J., Grundy, L., Castro, J., & Brierly, S. M. (2020). Pain in endometriosis. *Frontiers in Cellular Neuroscience*, 14, 1-16. <https://doi.org/10.3389/fncel.2020.590823>
- Maidment, J. (2020). Social work, mental health, and rural practice: A perspective from New Zealand. In T. A. Carey & J. Gullifer (Eds.), *Handbook of rural, remote and very remote*

*mental health* (pp. 1-18). Springer Nature Singapore. [https://doi.org/10.1007/978-981-10-5012-1\\_19-1#DOI](https://doi.org/10.1007/978-981-10-5012-1_19-1#DOI)

Maiese, M. (2014). How can emotions be both cognitive and bodily? *Phenomenology and the Cognitive Sciences*, 13(4), 513-531. <https://doi.org/10.1007/s11097-014-9373-z>

Márki, G., Bokor, A., Rigo, J., & Rigo, A. (2017). Physical pain and emotion regulation as the main predictive factors of health-related quality of life in women living with endometriosis. *Human Reproduction*, 32(7), 1432-1438. <https://doi.org/10.1093/humrep/dex091>

Martins, J., Ferreira, G., Vilaca, M., Ferreira, H., Osorio, F., Nogueira-Silva, C., & Pereira, M. G. (2022). Quality of life and sexual satisfaction in women with endometriosis: The moderator role of symptom severity. *Psychology & Sexuality*, 13(4), 952-964. <https://doi.org/10.1080/19419899.2021.1943501>

McCall, M. C. (2013). How might yoga work? An overview of potential underlying mechanisms. *Journal of Yoga & Physical Therapy*, 3(1), 1-6. <http://dx.doi.org/10.4172/2157-7595.1000130>

Medeiros De Bustos, E., Galli, S., Haffen, E., & Moulin, T. (2014). Clinical manifestations of hysteria: An epistemological perspective or how historical dynamics illuminate current practice. *Frontiers of Neurology and Neuroscience*, 35, 28-43. <https://doi.org/10.1159/000360436>

Mental Health Foundation. (2023). *Te whare tapa whā*. <https://mentalhealth.org.nz/te-whare-tapa-wha>

Miaskowski, C., Blyth, F., Nicosia, F., Haan, M., Keefe, F., Smith, A., & Ritchie, C. (2020). A biopsychosocial model of chronic pain for older adults. *Pain Medicine*, 21(9), 1793-1805. <https://doi.org/10.1093/pm/pnz329>

Mikocka-Walus, A., Druitt, M., O'Shea, M., Skvarc, D., Watts, J. J., Esterman, A., Tsaltas, J., Knowles, S., Harris, J., Dowding, C., Parigi, E., & Evans, S. (2021). Yoga, cognitive-behavioural therapy versus education to improve quality of life and reduce healthcare costs in people with endometriosis: A randomised controlled trial. *BMJ Open*, 11(8), 1-7. <https://doi.org/10.1136/bmjopen-2020-046603>

Ministry of Health. (2017). *Māori health models- Te whare tapa whā*. <https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha>

Ministry of Health. (2020). *Diagnosis and management of endometriosis in New Zealand*. <https://nzendo.org.nz/wp-content/uploads/2020/03/diagnosis-and-management-of-endometriosis-in-new-zealand-mar2020.pdf>

Ministry of Health. (2022). *Endometriosis*. <https://www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/endometriosis>

Missmer, S. A., Tu, F. F., Agarwal, S. K., Chapron, C., Soliman, A. M., Chiuve, S., Eichner, S., Flores-Caldera, I., Horne, A. W., Kimball, A. B., Laufer, M. R., Leyland, N., Singh, S. S.,

- Taylor, H. S., & As-Sanie, S. (2021). Impact of endometriosis on life-course potential: A narrative review. *International Journal of General Medicine*, 14, 9-25.  
<https://doi.org/10.2147%2FIJGM.S261139>
- Miyahara, K. (2021). Enactive pain and its sociocultural embeddedness. *Phenomenology and the Cognitive Sciences*, 20, 871-886. <https://doi.org/10.1007/s11097-019-09630-9>
- Montenegro, M. L., Bonoche, C. M., Meola, J., Portella, R. L., Ribeiro-Silva, A., Brunaldi, M. O., Ferriani, R. A., & Rosa-e-Silva, J. C. (2019). Effect of physical exercise on endometriosis experimentally induced in rats. *Reproductive Sciences*, 26(6), 785-793.  
<https://doi.org/10.1177/1933719118799205>
- Morotti, M., Vincent, K., Brawn, J., Zondervan, K. T., & Becker, C. M. (2014). Peripheral changes in endometriosis-associated pain. *Human Reproduction Update*, 20(5), 717-736.  
<https://doi.org/10.1093/humupd/dmu021>
- Morotti, M., Vincent, K., & Becker, C. M. (2017). Mechanisms of pain in endometriosis. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 209, 8-13.  
<https://doi.org/10.1016/j.ejogrb.2016.07.497>
- National Ethics Advisory Committee. (2023). 3. *Research and Māori*.  
<https://neac.health.govt.nz/national-ethical-standards/part-two/3-research-and-maori/>
- National Institute for Health and Care Excellence. (2017). *Endometriosis: Diagnosis and management*. NICE Guideline.  
<https://www.nice.org.uk/guidance/ng73/resources/endometriosis-diagnosis-and-management-pdf-1837632548293>
- National Institute of Neurological Disorders and Stroke. (2023). *Pain*.  
<https://www.ninds.nih.gov/health-information/disorders/pain#:~:text=What%20is%20pain%3F,%2C%20almost%20unnoticeable%2C%20or%20explosive.>
- New Zealand Register of Exercise Professionals. (2014). *Physical activity readiness questionnaire (PAR-Q)*. <https://www.reps.org.nz/wp-content/uploads/2017/04/REPs-PARQ-Form.pdf>
- Nezhat, C., Nguyen, K., Ackroyd, E., Roman, R. A., Rambhatla, A., Nezhat, A., & Asiaii, A. (2020). Nerve-sparing modified radical hysterectomy for severe endometriosis and complex pelvic pathology. *Cureus*, 12(8), 1-10. <https://doi.org/10.7759%2Fcureus.9882>
- Nirgianakis, K., Ma, L., McKinnon, B., & Mueller, M. D. (2020). Recurrence patterns after surgery in patients with different endometriosis subtypes: A long-term hospital-based cohort study. *Journal of Clinical Medicine*, 9(496), 1-11. <http://dx.doi.org/10.3390/jcm9020496>
- Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2022). A practical guide to reflexivity in qualitative research: AMEE guide no. 149. *Medical Teacher*, 45(3), 241-251.  
<https://doi.org/10.1080/0142159X.2022.2057287>
- Oxford University Innovation. (2016). *The endometriosis health profile (EHP)*.  
<https://innovation.ox.ac.uk/outcome-measures/endometriosis-health-profile-ehp/>

- Parasar, P., Ozcan, P., & Terry, K. L. (2017). Endometriosis: Epidemiology, diagnosis and clinical management. *Current Obstetrics and Gynecology Reports*, 6(1), 34-41. <https://doi.org/10.1007/s13669-017-0187-1>
- Parazzini, F., Vigano, P., Candiani, M., & Fedele, L. (2013). Diet and endometriosis risk: A literature review. *Reproductive BioMedicine Online*, 26(4), 323-336. <https://doi.org/10.1016/j.rbmo.2012.12.011>
- Parazzini, F., Esposito, G., Tozzi, L., Noli, S., & Bianchi, S. (2017). Epidemiology of endometriosis and its comorbidities. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 209, 3-7. <https://doi.org/10.1016/j.ejogrb.2016.04.021>
- Park, S. B. (2014). Features of the hypointense solid lesions in the female pelvis on T2-weighted MRI. *Journal of Magnetic Resonance Imaging*, 39(3), 493-503. <https://doi.org/10.1002/jmri.24512>
- Parra, R. S., Feisto, M. R., Parra de Camargo, H., Valerio, F. P., Zanardi, J. V. C., Ribeiro da Rocha, J. J., & Feres, O. (2021). The impact of laparoscopic surgery on the symptoms and wellbeing of patients with deep infiltrating endometriosis and bowel movement. *Journal of Psychosomatic Obstetrics & Gynecology*, 42(1), 75-80. <https://doi.org/10.1080/0167482X.2020.1773785>
- PayScale. (2023). *Average yoga instructor hourly pay in New Zealand*. [https://www.payscale.com/research/NZ/Job=Yoga\\_Instructor/Hourly\\_Rate](https://www.payscale.com/research/NZ/Job=Yoga_Instructor/Hourly_Rate)
- Pitama, S. G., Bennett, S. T., Waitoki, W., Haitana, T. N., Valentine, H., Pahina, J., Taylor, J. E., Tassell-Matamua, N., Rowe, L., Beckert, L., Palmer, S. C., Huria, T. M., Lacey, C. J., & McLachlan, A. (2017). A proposed hauora Māori clinical guide for psychologists: Using the hui process and meihana model in clinical assessment and formulation. *New Zealand Journal of Psychology*, 46(3), 7-19. [https://researchcommons.waikato.ac.nz/bitstream/handle/10289/12516/NZJP\\_Vol46%20No3\\_A%20proposed%20Hauora%20Mori%20Clinical%20Guide%20for%20Psychologists.pdf?sequence=2&isAllowed=y](https://researchcommons.waikato.ac.nz/bitstream/handle/10289/12516/NZJP_Vol46%20No3_A%20proposed%20Hauora%20Mori%20Clinical%20Guide%20for%20Psychologists.pdf?sequence=2&isAllowed=y)
- Pitot, M. A., Bookwalter, C. A., Dudiak, K. M. (2020). Müllerian duct anomalies coincident with endometriosis: A review. *Abnormal Radiology*, 45, 1723-1740. <https://doi.org/10.1007/s00261-020-02465-y>
- Poordast, T., Alborzi, S., Askary, E., Tavabe, M. S., Najib, F. S., Salehi, A., Vardanjani, H. M., Haghghat, N., & Leilami, K. (2022). Comparing the quality of life of endometriotic patients' before and after treatment with normal and infertile patients based on the EHP30 questionnaire. *BMC Women's Health*, 22(553), 1-11. <https://doi.org/10.1186/s12905-022-02052-x>
- Popova, Y. B., & Raczaszek-Leonardi, J. (2020). Enactivism and ecological psychology: The role of bodily experience in agency. *Frontiers in Psychology*, 11, 1-16. <https://doi.org/10.3389/fpsyg.2020.539841>

## ENDOMETRIOSIS & YOGA

- Rahmioglu, N., Montgomery, G. W., & Zondervan, K. T. (2015). Genetics of endometriosis. *Women's Health, 11*(5), 577-586. <https://doi.org/10.2217/whe.15.41>
- Rizk, B., Fischer, A. S., Lofty, H. A., Turki, R., Zahed, H. A., Malik, R., Holliday, C. P., Glass, A., Fishel, H., Soliman, M. Y., & Herrera, D. (2014). Recurrence of endometriosis after hysterectomy. *Facts, Views & Vision in Obgyn, 6*(4), 219-227. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4286861/pdf/FVVinObGyn-6-219-227.pdf>
- Royal Melbourne Institute of Technology (RMIT) (2022). *Answers to frequently asked questions about thematic analysis, schemes and mind maps for qualitative research*. <https://www.docsity.com/en/answers-to-frequently-asked-questions-about-thematic-analysis/8744729/>
- Ruszala, M., Dluski, D. F., Winkler, I., Kotarski, J., Rechberger, T., & Gogacz, M. (2022). The state of health and the quality of life in women suffering from endometriosis. *Journal of Clinical Medicine, 11*(2059), 1-9. <https://doi.org/10.3390/jcm11072059>
- Schick, M., Germeyer, A., Bottcher, B., Hecht, S., Geiser, M., Rosner, S., Eckstein, M., Vomstein, K., Toth, B., Strowitzki, T., Wischmann, T., & Bitzen, B. (2022). Partners matter: The psychosocial well-being of couples when dealing with endometriosis. *Health and Quality of Life Outcomes, 20*(86), 1-10. <https://doi.org/10.1186/s12955-022-01991-1>
- Schmidt, P. (2022). Variety in the experience of pain and its explanation. *Constructivist Foundations: An Interdisciplinary Journal, 17*(2), 154-156. <https://eds.s.ebscohost.com/eds/pdfviewer/pdfviewer?vid=1&sid=eb7b2499-5004-4f32-8fef-280bf266fc7e%40redis>
- Singh, G., Newton, C., O'Sullivan, K., Soundy, A., & Heneghan, N. R. (2018). Exploring the lived experience and chronic low back pain beliefs of English-speaking Punjabi and white British people: A qualitative study within the NHS. *British Medical Journal Open, 8*(2), 1-11. <https://doi.org/10.1136/bmjopen-2017-020108>
- Situmorang, H., Avriyani, R. L., & Gunardi, E. R. (2019). The association between endometriosis appearance during laparoscopic surgery and pain characteristic in pelvic endometriosis. *Indonesian Journal of Obstetrics and Gynecology, 7*(2), 116-121. <https://doi.org/10.32771/inajog.v7i2.831>
- Smrdu, M. (2022). Kaleidoscope of pain: What and how do you see through it. *Constructivist Foundations, 17*(2), 136-147. <https://constructivist.info/17/2/136>
- Soliman, A. M., Surrey, E., Bonafede, M., Nelson, J. K., & Castelli-Haley, J. (2018). Real-world evaluation of direct and indirect economic burden among endometriosis patients in the United States. *Advances in Therapy, 35*, 408-423. <https://doi.org/10.1007/s12325-018-0667-3>
- Sourial, S., Tempest, N., & Hapangama, D. K. (2014). Theories on the pathogenesis of endometriosis. *International Journal of Reproductive Medicine, 2014*(179515), 1-9. <http://dx.doi.org/10.1155/2014/179515>

## ENDOMETRIOSIS & YOGA

- Statistics New Zealand. (2018). *2018 Census ethnic group summaries*.  
<https://www.stats.govt.nz/tools/2018-census-ethnic-group-summaries>
- Stenfors, T., Kajamaa, A., & Bennett, D. (2020). How to...assess the quality of qualitative research. *The Clinical Teacher*, 17(6), 596-599. <https://doi.org/10.1111/tct.13242>
- Stilwell, P., & Harman, K. (2019). An enactive approach to pain: Beyond the biopsychosocial model. *Phenomenology and the Cognitive Sciences*, 18, 637-655.  
<https://doi.org/10.1007/s11097-019-09624-7>
- Stutchbury, K. (2022). Critical realism: An explanatory framework for small-scale qualitative studies or an 'unhelpful edifice'? *International Journal of Research & Method in Education*, 45(2), 113-128. <https://doi.org/10.1080/1743727X.2021.1966623>
- Subedi, K. R. (2021). Determining the sample in qualitative research. *Scholars' Journal*, 4, 1-13.  
<http://dx.doi.org/10.3126/scholars.v4i1.42457>
- Sutherland, S. (2022). What is pain? *New Scientist*, 256(3413), 38-39.  
[https://doi.org/10.1016/S0262-4079\(22\)02088-7](https://doi.org/10.1016/S0262-4079(22)02088-7)
- Tasca, C., Rapetti, M., Carta, M. G., & Fadda, B. (2012). Women and hysteria in the history of mental health. *Clinical Practice & Epidemiology in Mental Health*, 8, 110-119.  
<https://doi.org/10.2174%2F1745017901208010110>
- Tassell, N. A., Herbert, A. M. L., Evans, I. M., & Young, P. T. W. A. (2012). Principles of indigenous ethics and psychological interventions. In A. Ferrero, Y. Korkut, M. M. Leach, G. Lindsay & M. J. Stevens. *The Oxford handbook of international psychological ethics* (pp. 176-190). Oxford University Press.  
<https://doi.org/10.1093/oxfordhb/9780199739165.013.0013>
- Tavares de Arruda, G., Driusso, P., Rodrigues, J. C., Garcia de Godoy, A., & Avila, M. A. (2022). Numerical rating scale for dysmenorrhea-related pain: A clinimetric study. *Gynecological Endocrinology*, 38(8), 661-665. <https://doi.org/10.1080/09513590.2022.2099831>
- Taylor, H. S., Soliman, A. M., Johns, B., Pokrzywinski, R. M., Snabes, M., & Coyne, K. S. (2020). Health-related quality of life improvements in patients with endometriosis treated with elagolix. *Obstetrics & Gynecology*, 136(3), 501-509.  
<https://doi.org/10.1097/aog.0000000000003917>
- Teng, W. S. (2023). *Why TCM experts say to avoid cold foods*. Oriental Medical Care.  
<https://orientalmedicalcare.com/2023/02/10/why-tcm-experts-say-to-avoid-cold-foods/>
- Tennfjord, M. K., Gabrielsen, R., & Tellum, T. (2021). Effect of physical activity and exercise on endometriosis-associated symptoms: A systematic review. *BMC Women's Health*, 21(355), 1-10. <https://doi.org/10.1186/s12905-021-01500-4>
- Teoli, D., & Bhardwaj, A. (2022). *Quality of life*. StatPearls Publishing.  
<https://www.ncbi.nlm.nih.gov/books/NBK536962/?report=classic>

- Tewhaiti-Smith, J., Semprini, A., Bush, D., Anderson, A., Eathorne, A., Johnson, N., Girling, J., East, M., Marriott, J., & Armour, M. (2022). An Aotearoa New Zealand survey of the impact and diagnostic delay for endometriosis and chronic pelvic pain. *Scientific Reports*, 12(4425), 1-9. <https://doi.org/10.1038/s41598-022-08464-x>
- Timotin, I., Ganenco, A., Lozovanu, S., Arnaut, O., Grabovschi, I., Moldovanu, I., & Vovc, V. (2023). The role of depression and anxiety in pain perception. *Moldovan Medical Journal*, 66(1), 24-30. <https://doi.org/10.52418/moldovan-med-j.66-1.23.04>
- Tourny, C., Zouita, A., El Kababi, S., Feuillet, L., Saeidi, A., Laher, I., Weiss, K., Knechtle, B., & Zouhal, H. (2023). Endometriosis and physical activity: A narrative review. *International Journal of Gynecology & Obstetrics*, 1-10. <https://doi.org/10.1002/ijgo.14898>
- Tracy, S. J. (2020). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact* (2nd ed.). John Wiley & Sons.
- Treloar, S. A., O'Connor, D. T., O'Connor, V. M., & Martin, N. G. (1999). Genetic influences on endometriosis in an Australian twin sample. *Fertility and Sterility*, 71(4), 701-710. [https://doi.org/10.1016/S0015-0282\(98\)00540-8](https://doi.org/10.1016/S0015-0282(98)00540-8)
- Triolo, O., Lagana, A. S., & Sturlese, E. (2013). Chronic pelvic pain in endometriosis. *Journal of Clinical Medicine Research*, 5(3), 153-163. <https://doi.org/10.4021%2Fjocmr1288w>
- Uccella, S., Marconi, N., Casarin, J., Ceccaroni, M., Boni, L., Strula, D., Serati, M., Carollo, S., Alluvion, C. P., & Ghezzi, F. (2016). Impact of endometriosis on surgical outcomes and complications of total laparoscopic hysterectomy. *Archives of Gynecology and Obstetrics*, 294, 771-778. <https://doi.org/10.1007/s00404-016-4115-9>
- Urban, E. J., Cochran, K. J., Acevedo, A. M., Cross, M. P., Pressman, S. D., & Loftus, E. F. (2019). Misremembering pain: A memory blindness approach to adding a better end. *Memory & Cognition*, 47(5), 954-967. <https://doi.org/10.3758%2Fs13421-019-00913-9>
- Van Niekerk, L. M., Steains, E., & Matthewson, M. (2022). Correlates of health-related quality of life: The influence of endometriosis, body image and psychological wellbeing. *Journal of Psychosomatic Research*, 161(110993), 1-7. <https://doi.org/10.1016/j.jpsychores.2022.110993>
- Van Poll, M., Van Barneveld, E., Aerts, L., Maas, J. W. M., Lim, A. C., De Greef, B. T. A., Bongers, M. Y., & Van Hanegem, N. (2020). Endometriosis and sexual quality of life. *Sexual Medicine*, 8(3), 532-544. <https://doi.org/10.1016/j.esxm.2020.06.004>
- Van Stein, K., Schubert, K., Ditzen, B., & Weise, C. (2023). Understanding psychological symptoms of endometriosis from a research domain criteria perspective. *Journal of Clinical Medicine*, 12(12), 1-14. <https://doi.org/10.3390/jcm12124056>
- Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: Systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, 18, 1-18. <https://doi.org/10.1186/s12874-018-0594-7>

## ENDOMETRIOSIS & YOGA

- Verket, N. J., Andersen, M. H., Sandvik, L., Tanbo, T. G., & Qvigstad, E. (2018). Lack of cross-cultural validity of the endometriosis health profile-30. *Journal of Endometriosis and Pelvic Pain Disorders*, 10(2), 107-115. <https://doi.org/10.1177/2284026518780638>
- Vitale, S. G., La Rosa, V. L., Rapisarda, A. M. C., & Lagana, A. S. (2017). Impact of endometriosis on quality of life and psychological well-being. *Journal of Psychosomatic Obstetrics & Gynecology*, 38(4), 1-3. <http://dx.doi.org/10.1080/0167482X.2016.1244185>
- Warburton, D. E. R., Jamnik, V., Bredin, S. S. D., Shephard, R., & Gledhill, N. (2021). The 2021 physical activity readiness questionnaire for everyone (PAR-Q+) and electronic physical activity readiness medical examination (ePARmed-X+). *The Health & Fitness Journal of Canada*, 14(1), 1-4. <https://hfjc.library.ubc.ca/index.php/HFJC/article/view/103/66>
- Wellman, J. D., Araiza, A. M., Newell, E. E., & McCoy, S. K. (2018). Weight stigma facilitates unhealthy eating and weight gain via fear of fat. *Stigma Health*, 3(3), 186-194. <https://doi.org/10.1037%2Fsah0000088>
- Women's Health Action. (n.d.). *Endometriosis*. <https://www.womens-health.org.nz/endometriosis/>
- World Health Organization. (2012). *Programme on mental health: WHOQOL user manual*. <https://www.who.int/publications/i/item/WHO-HIS-HSI-Rev.2012.03>
- World Health Organization. (2023a). *Endometriosis*. <https://www.who.int/news-room/fact-sheets/detail/endometriosis>
- World Health Organization. (2023b). *WHOQOL: Measuring quality of life*. <https://www.who.int/tools/whoqol>
- Wyeth, E. H., Derrett, S., Hokowhitu, B., Samaranayanka, A. (2013). Indigenous injury outcomes: Life satisfaction among injured Māori in New Zealand three months after injury. *Health and Quality of Life Outcomes*, 11(120), 1-9. <https://hqlo.biomedcentral.com/articles/10.1186/1477-7525-11-120>
- Young, K., Fisher, J., & Kirkman, M. (2018). "Do mad people get endo, or does endo make you mad?": Clinicians' discursive constructions of medicine and women with endometriosis. *Feminism & Psychology*, 29(9), 337-356. <https://doi.org/10.1177/0959353518815704>
- Young, K., Fisher, J., & Kirkman, M. (2020). Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis. *Feminism & Psychology*, 30(1), 22-41. <https://doi.org/10.1177/0959353519826170>
- Zhang, T. (2023). Critical realism: A critical evaluation. *Social Epistemology*, 37(1), 15-29. <https://doi.org/1080/02691728.2022.2080127>

## Appendices

### Appendix A: Cultural Plan (Protocols) for Māori Participants

Pretty Samudraningsih

ID: [REDACTED]

#### **Endometriosis & Savasana: Exploring Pain Management for Endometriosis Through the Practice of Yoga**

Pretty Samudraningsih [REDACTED]  
Master's thesis

Project Detail and Protocols for Māori Participants

I am currently in the process of completing my full ethics application through the ethics committee for my qualitative/exploratory research on the effectiveness of yoga as a method of pain management for endometriosis. This research will include a maximum of 10 women, over the course of 12 weeks. This research will not specifically focus on Māori or Māori women, but it is open to all women who live in Auckland, New Zealand, who have been laparoscopically diagnosed with endometriosis.

#### Research aim:

This study will aim to investigate the effectiveness of yoga as a pain management mediation for endometriosis and its symptoms. Specifically, this study will investigate the experiences of women who have endometriosis in Aotearoa New Zealand whilst practicing yoga, analysing any changes in their experienced pain, mental wellbeing and also their perceived overall health.

#### Research outline:

My research is to study the effectiveness of yoga as a pain management mediation for endometriosis. I intend to include female participants aged between 18-50 years old, who have been laparoscopically diagnosed with endometriosis. The study will run for a total of 12 weeks. Participants will complete a 25-question endometriosis survey at the start and end of the research, and complete a shorter version (5 questions) 8 weeks into the research. Participants are to write in self-report diaries everyday of their level of pain. Participants can also include additional information in their diaries, such as their moods, any exercises or physical activity they did, and elaborate on their level of pain and menstrual bleeding, etc. The yoga intervention will only be introduced after 4 weeks, and participants will practice 2x yoga sessions per week for the next 8 weeks. Twice-a-week (before and after yoga sessions), the participants are to also record their level of pain before and after each yoga session. The yoga instructor will be advised to teach a form of yoga that is most suitable for beginners and focuses on relaxation and mindfulness. If any participants feel any discomfort or pain during the yoga sessions, the instructor can give variations of the poses so as to reduce their pain. They may also take a break, leave the class, or even withdraw. At the end of the 12 weeks, participants will individually meet with the researcher for a semi-structured interview to describe their experience throughout the research, any changes they may have seen, what information they have learned, etc.

**Endometriosis & Savasana: Exploring Pain Management for Endometriosis Through the Practice of Yoga**

Pretty Samudraningsih [REDACTED]  
Master's thesis  
Project Detail and Protocols for Māori Participants

I am currently in the process of completing my full ethics application through the ethics committee for my qualitative/exploratory research on the effectiveness of yoga as a method of pain management for endometriosis. This research will include a maximum of 10 women, over the course of 12 weeks. This research will not specifically focus on Māori or Māori women, but it is open to all women who live in Auckland, New Zealand, who have been laparoscopically diagnosed with endometriosis.

**Research aim:**

This study will aim to investigate the effectiveness of yoga as a pain management mediation for endometriosis and its symptoms. Specifically, this study will investigate the experiences of women who have endometriosis in Aotearoa New Zealand whilst practicing yoga, analysing any changes in their experienced pain, mental wellbeing and also their perceived overall health.

**Research outline:**

My research is to study the effectiveness of yoga as a pain management mediation for endometriosis. I intend to include female participants aged between 18-50 years old, who have been laparoscopically diagnosed with endometriosis. The study will run for a total of 12 weeks. Participants will complete a 25-question endometriosis survey at the start and end of the research, and complete a shorter version (5 questions) 8 weeks into the research. Participants are to write in self-report diaries everyday of their level of pain. Participants can also include additional information in their diaries, such as their moods, any exercises or physical activity they did, and elaborate on their level of pain and menstrual bleeding, etc. The yoga intervention will only be introduced after 4 weeks, and participants will practice 2x yoga sessions per week for the next 8 weeks. Twice-a-week (before and after yoga sessions), the participants are to also record their level of pain before and after each yoga session. The yoga instructor will be advised to teach a form of yoga that is most suitable for beginners and focuses on relaxation and mindfulness. If any participants feel any discomfort or pain during the yoga sessions, the instructor can give variations of the poses so as to reduce their pain. They may also take a break, leave the class, or even withdraw. At the end of the 12 weeks, participants will individually meet with the researcher for a semi-structured interview to describe their experience throughout the research, any changes they may have seen, what information they have learned, etc.

Principles underpinning the research:

- The researcher has read Te Ara Tika and includes elements of this within her research design.
- The research and interview process will reflect Māori values/customs and demonstrate a commitment to the principles of partnership, protection, and participation of Te Tiriti o Waitangi.
- This research will incorporate a partnership approach, aiming to form positive relationships (whakawhanaungatanga), advocate for participants to have autonomy throughout the research, be transparent and honest regarding the research and all procedures, and will ensure that value is embedded in the research.
- This research will acknowledge and will emphasise participants' experiences, recognising individualistic views on health, quality of life and their lived experiences.

Treaty of Waitangi/cultural considerations:

This research will be conducted in a way that upholds the principles of the Treaty of Waitangi, by making sure that I uphold the Treaty's principles of partnership, protection and participation. This study will not solely focus on Māori participants, however they will have the opportunity to be involved should they wish. If there are any Māori participants involved in the research, I will respect their culture, dignity and any protocols to ensure the participant feels that their cultural values are understood and respected. I will be sensitive and not make any assumptions regarding any practices (e.g., I will not assume they will want to do a karakia during the interview process, but will ask them if they would like to conduct a karakia before and/or after the meeting, ask if they would like to bring a whanau member to interviews). Should I have any queries regarding following appropriate cultural protocols, I can seek advice from Māori Massey professors and my thesis supervisor, Dr Kathryn McGuigan.

Face-to-face interviews will be held with the participants for this study. This is to ensure that a relationship can be built (whakawhanaungatanga) and so that the researcher can be open in sharing the details and information of the research with the participant (mohiotanga). This way, trust and manaakitanga can be practiced. The researcher has read and understood Te Ara Tika. If Māori participants want to be involved in the research (and match the inclusion criteria), the researcher will make sure to respect the Te Ara Tika (Māori research ethics guidelines) and Treaty of Waitangi.

The findings from this research will be used to describe the sample, and will not be generalised to Māori or any ethnic group. As this is a small sample, I understand that there may be limitations in diversity or relatability in the ethnicities of the participants, and that the ethnicities of the participants may not totally resemble the diversity of ethnicities in our NZ community. I can discuss this as a limitation in our study, and although the research and its findings are not focused on any specific ethnic groups, the findings will be beneficial to share with the wider NZ community, across all ethnic groups such as the Māori community, as women from different backgrounds are affected by endometriosis.

The findings will be presented in my Master's thesis. The findings will also be presented to the participants should they request to see the results and findings of the research. The findings of the research themselves can be separately presented to any Māori lecturers at

Massey University, upon request, and the findings, as well as my thesis, will be shown to Dr Kathryn McGuigan, my supervisor.

Maximising benefit and minimising risk of harm:

The researcher will uphold Te Ao Māori and respect each individual and their values. The researcher will ensure the mana and tikanga of each participant is upheld. This includes:

- Acknowledging the diversity of Māori and cultural contexts. I will not assume and therefore ask each participant how they would like to go ahead with the interviews. If they would like to implement any cultural practices, for example a karakia, or if they would like myself, the researcher, or themselves to bring kai to the meetings. The overarching principle is that each individual is different and independent, and can choose preferences for themselves.
- Following a hui (gathering) process that is personalised to each individual and includes four key elements: mihi (greeting and expression of thanks), whakawhānaungatanga (forming positive relationships), kaupapa (purpose) and poroporoaki (closing the session). The researcher will check to see if the participant would like to share their pepeha (self-introduction) or whakapapa (genealogy/relationships). Researcher will ensure there is plenty of time for introductions and whakawhānaungatanga (establishing connection), ask if they would like to start or close with a karakia, and ask if the participant would like the researcher to provide kai for the interviews.
- The researcher can only speak English, so the interviews and documentation will be in English. Participants will be informed of this, and the researcher will incorporate Te Reo when possible, such as karakia and greetings.
- All interviews will be kanohi-ki-te-kanohi (face-to-face) where possible, unless participants prefer/are only able to have online interviews.
- Providing opportunities for informed decision-making, self-determination and autonomy. Participation is voluntary.
- Participants will have autonomy over their withdrawal- they will be informed that they can withdraw up to 6 weeks since the research start date. They also have autonomy over where they would like the interviews to be conducted (e.g., in a private setting such as their home, or in a public setting such as a library). They will be able to choose if and who they would like to bring to the interviews (whanau or support person), and will be able to choose what they would like to share (they can decline to answer any questions they are not comfortable in sharing, and ask to stop the interview at any point).
- They will have the right to read transcripts of the interviews and see if they would like to make any changes, if they approve or if they decline transcripts.
- They have the right to have their identities made anonymous so that their privacy and confidentiality is kept. Data that include identities (e.g., name) will be made anonymous and pseudonyms can be used if referring to the participant's information, with their consent.
- Participants will be given koha in the form of a \$20 fuel voucher as an acknowledgement and gratitude for their time and participation in the research.

Practice of reflection:

Having reflexivity is an important criteria for qualitative research in order to help the researcher recognise any personal biases and pre-understandings, such as:

- Impact of colonisation.
- Influence of culture on different world views of health (researcher's own cultural values and background, as well as the participants' cultural views and practices and how this influences their views on health and illness).
- Understanding the impact of individualistic and collectivist views on health and illness, and understanding a holistic view of health, the interconnectedness between mind, body, spirit and experience.
- Understand how health and quality of life is complex, and can be viewed through many lenses and contexts (physiology, social, psychological and experiences).

Seeking guidance:

I will seek guidance and support from my thesis supervisor, Dr Kathryn McGuigan. If I am unsure how to proceed with any protocols or need further consultation regarding upholding Māori values/customs, I will seek guidance from Dr Kathryn McGuigan and contact Māori professors from Massey University if required.

**Appendix B: Advertisements**

1. Facebook Advertisements for Participants:

# WOMEN WANTED

Do you have endometriosis?  
Is the pain impacting your everyday life?  
Volunteer female participants needed for research!

Approximately 1 in 10 women in NZ have endometriosis. Common symptoms include painful periods and bowel movements, chronic pelvic pain, and fatigue. Unfortunately, diagnosis and effective treatments are still ambiguous.



## What is the research?

- To study the effectiveness of yoga in managing pain caused by endometriosis.
- The study will run for a total of 12 weeks.

## Criteria?

- Females aged between 18–50 years old.
- Clinically diagnosed with endometriosis.
- Willing to practice yoga and comfortable with discussing personal endometriosis journey.

*\*\*Exclusion criteria apply, please contact for more information\*\**

## Why get involved?

- Potential benefits for your mental and physical health.
- Contributing towards research & spreading awareness.

**For more information, please contact:**

**Pretty Samudraningsih**

**pretty\_sn11@hotmail.com // [REDACTED]**



2. Facebook Advertisement for Yoga Instructor:

**YOGA INSTRUCTORS WANTED**

Are you a qualified yoga instructor?  
Want to be part of a health research looking at  
endometriosis?


**What is the research?**

- University research studying the effectiveness of yoga in managing pain caused by endometriosis.

**Information:**

- Qualified yoga instructor needed to coordinate 2x yoga classes per week for 8 weeks to participants in the study.
- Each session is to run for 60 minutes.
- Must be able to coordinate/teach a form of yoga suitable for beginners (e.g. Hatha yoga).
- Will be paid \$30 per session.

**For more information, please contact:**  
**Pretty Samudraningsih**  
[pretty\\_sn11@hotmail.com](mailto:pretty_sn11@hotmail.com) / [REDACTED]



3. Instagram Story Advertisement for Participants:



## Appendix C: Information Sheets

### 1. Participant Information Sheet:

School of Psychology  
Massey University  
Private Bag 102-904  
North Shore  
Auckland 0745



COLLEGE OF  
HUMANITIES AND  
SOCIAL SCIENCES

### *Endometriosis & Savasana: Exploring Pain Management for Endometriosis Through the Practice of Yoga*

#### INFORMATION SHEET

##### **Researcher introduction:**

Kia ora, thank you for your interest in this research project. My name is Pretty Samudraningsih and I am a student in the Master of Arts programme at Massey University, majoring in Psychology.

##### **Project description:**

The purpose of conducting this research is to investigate women's journeys with endometriosis, and how pain caused by endometriosis has affected them. I am inviting women who have endometriosis and are residing in Auckland, New Zealand to be part of this health research. This research will focus specifically on yoga as a pain management approach, with the aim to assess its effectiveness in reducing pain caused by endometriosis.

##### **Participant selection and recruitment:**

The selection criteria are as follows:

- Females aged between 18-50 years old.
- Laparoscopically diagnosed with endometriosis (can be in any stage, 1-4).
- Living in Auckland, New Zealand.
- Individuals generally fit and well.
- Willing to practice yoga 2x per week for 8 weeks and participate in the study for a total of 12 weeks.
- Experiencing on average at least a moderate level of pain regularly due to endometriosis.

Exclusion criteria are as follows:

- Pregnant
- Currently practicing yoga (1 or more times per week).
- Regularly exercises (2 or more times per week).
- Have a serious illness which affects ability to do yoga poses (e.g., multiple sclerosis).

*If you would like to participate in this study but feel that you are unsure of your health condition, please consult with your GP first to ensure that you are well and fit to practice yoga, and for the duration of this study.*

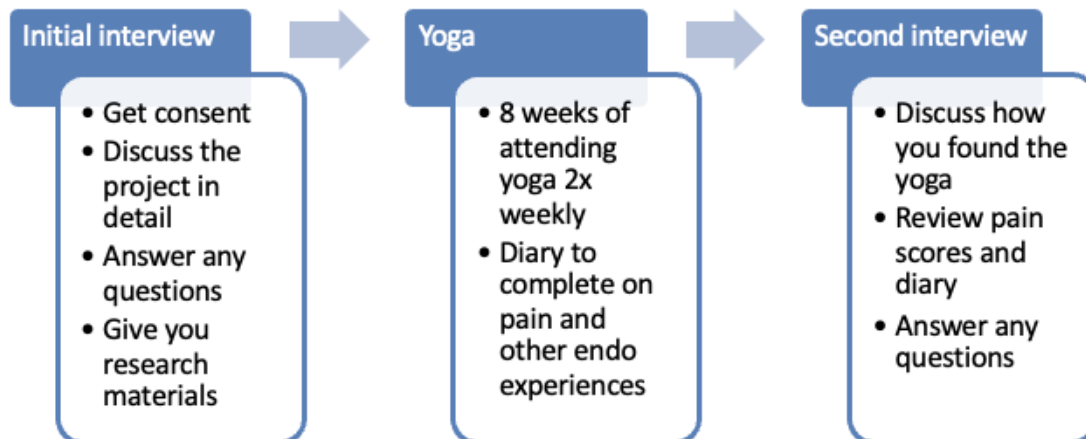
Please note that participation in this research will be voluntary and you will have the right to withdraw from the research. You will be able to withdraw from the study at any point throughout the 12 weeks.

*If you withdraw within 6 weeks of the research start date, any data or information you have provided up to the point of withdrawal will be used in the research. If you wish for the information you provided to not be included as part of the research, please specify this with me (researcher). However, if you withdraw after 6 weeks of the research start date, any data or information you have provided up until the point of withdrawal will be used in the research and cannot be requested to be excluded from the research.*

Upon completion of the study, at the end of the 12 weeks, participants will receive a \$20 fuel voucher.

## **What is involved?**

The study is summarized in the graph below.



### ***Initial interview:***

I will arrange an initial meeting with you where I will ask about your endometriosis history and your journey, answer any questions you might have regarding the study and gain consent. I will also ask what level of pain you experience due to your endometriosis. I will collect general details about you, such as age, ethnicity, occupation, etc. I will bring along physical copies of written consent forms for you to complete and will go through this with you in detail. I will give you two questionnaires and a diary to take home with you, to use once the study begins. Please note that this meeting will be recorded using an audio recorder. You may ask for the recorder to be turned off at any time.

This initial meeting can be held in a private, quiet location, such as your home, or in a quiet public area that will ensure your privacy. You are more than welcome to bring along anything that makes you comfortable, such as bringing along a support person (e.g., family member or friend), or objects of support. I expect that the meeting will be approximately 60-90 minutes.

### ***Yoga phase:***

On the start day of the research, please fill out **ONE** of the questionnaires that was given to you at the initial meeting (25 questions – 10 mins to complete). A diary was also given to you at the initial meeting, please start using this diary once the research begins. In this diary, there will be one question you have to answer every day for the next 12 weeks. If possible, please answer this question at the same time every day:

1. “How much pain did you experience today?”. Please answer between 0 (no pain at all) to 10 (most extreme pain).

Whilst answering this question every day, it is recommended to also write additional information in the diary. For example, you may wish to write your moods and emotions, any physical activities you did, if you felt pain what you did to relieve it, your menstrual pattern, etc. I advise that you treat this diary like a personal diary, and you can include any information you like. You do not need to spend too much time writing in the diary, approximately 5 minutes should be fine.

School of Psychology  
Massey University  
Private Bag 102-904  
North Shore  
Auckland 0745



COLLEGE OF  
HUMANITIES AND  
SOCIAL SCIENCES

The yoga sessions will begin 4 weeks into the study and will be conducted by a qualified yoga instructor. Attendance for the yoga sessions will be 2x per week for the next 8 weeks, until the research finishes. During the day you have yoga, we would like you to answer question #1 ("how much pain did you experience today?") in your diary before and after the yoga session. Please still continue to include any additional information/comments about your day. If during the yoga sessions you may feel any discomfort or pain, please advise the yoga instructor and they may give you a different variation of a pose, to reduce the pain. You may also take a break at any point during the yoga session if you feel any discomfort or pain, and if required, you may also leave the class if you can no longer continue.

Halfway through the study (8 weeks into the research project and 4 weeks since the yoga sessions started), you will find in your diary a short questionnaire (5 questions – 5 mins to complete). This questionnaire will include some questions related to your endometriosis. Please answer these questions reflecting on your experience within the last 4 weeks. I will send you a text reminder.

On the last day of the research (end of 12 weeks), please fill out the **second** questionnaire that was given to you at the initial meeting (25 questions – 10 mins to complete).

### ***Interview two:***

I will invite you to an interview (time commitment approx. 30 – 60 mins). **Please bring your diary and questionnaires to the interview.** In the interview, I will ask you about your experience with the research, how you found it, if you noticed any changes, etc. We will meet in a location that ensures your privacy and anywhere you feel comfortable. I will record the interviews using an audio recorder and you may ask to stop the recording at any point. I will record our conversations so I can remember what was said and transcribe it into a written document.

I will then email you the transcripts of our initial interview and the second interview. You will have 2 weeks to read and respond to the transcripts, whether or not you would like to make any changes, and if you approve it. If no response is given after 2 weeks, I will assume you approve. At the end of the research project, I will provide you with a summary of the findings if you request this.

### **Potential benefits and risks of this research:**

Some benefits to participating in this research is that participants will practice yoga for free for 8 weeks. You will have the opportunity to practice and implement yoga poses, breathing techniques and mindfulness exercises, which can be helpful for improving flexibility and mental health. This research will also bring together women from different backgrounds and endometriosis journeys. This can help build a sense of belonging by being able to get together with other women who are going through similar things as you, being able to share and relate to experiences, knowing that you are not alone and have a support group.

With any research, there is always a potential for risks and discomfort. If at any point throughout the research, you feel any discomfort talking about specific topics or recalling your history, please advise me and we can skip such questions. You are welcome to share anything that you choose and are not obligated to disclose information you do not feel comfortable in sharing. Information of some support organisations are at the end of this sheet. Your identity and information will also be omitted so you will not be identified (e.g., your name, place of residence and work).

During the yoga sessions, should you feel any discomfort or pain, please advise the yoga instructor. You may stop at any point or leave the class if required. The yoga instructor can give you variations of a pose to reduce the pain, you may take a break to relax, and you may leave the class if you wish.

School of Psychology  
Massey University  
Private Bag 102-904  
North Shore  
Auckland 0745



COLLEGE OF  
HUMANITIES AND  
SOCIAL SCIENCES

### **Compensation for injury:**

If you have any concerns regarding your health and ability to practice yoga for this research, **please consult your GP first**, and if necessary, obtain a signed note from them.

If physical injury results from your participation in this study, you should visit a treatment provider to make a claim to ACC as soon as possible. ACC cover and entitlements are not automatic and your claim will be assessed by ACC in accordance with the Accident Compensation Act 2001. If your claim is accepted, ACC must inform you of your entitlements, and must help you access those entitlements. Entitlements may include, but are not limited to, treatment costs, travel costs for rehabilitation, loss of earnings, and/or lump sum for permanent impairment. Compensation for mental trauma may also be included, but only if this is incurred as a result of physical injury.

If your ACC claim is not accepted, you should immediately contact me, the researcher. I will initiate processes to ensure you receive compensation equivalent to which you would have been entitled, had ACC accepted your claim.

### **Data management:**

Your confidentiality and privacy are very important. All names and identifying information will be removed from transcripts, data and write up of this research. I will ask for your permission when transcribing our discussion and use pseudonyms. I will store the transcripts in a password-protected file on a computer. I will show you the transcripts and once you approve, I will delete the audio recordings. I will digitise your consent forms and store them in a password-protected file on a computer, and store the physical copies of the consent forms in a locked cabinet. Once the research is completed, all documents will be destroyed following Massey University's document destruction and privacy policies.

Deidentified data will be kept for 7 years. This will be kept in the Massey Microsoft OneDrive. Data will be erased from all computers and hard drives used. Any hard copies of identified data (e.g., consent forms) will be shredded upon completion of study. All identified data will be made anonymous and held securely on a protected Massey disk data storage system (H drive). Codes will identify participants with one master list of the allocated codes kept on the supervisor's hard drive. All other anonymised information will be stored on the researcher's Massey OneDrive (password protected). All audio recordings will be deleted upon transcription, all transcripts and unused timelines will be destroyed upon the study's completion. Any identifiable data, such as signed consent forms, will be stored in either a locked drawer in the supervisor's (Dr Kathryn McGuigan) office or on their H drive. Only the student researcher and supervisor can access the data. All unidentified data will be held securely for 7 years by Dr Kathryn McGuigan and then destroyed (including research notes, findings, etc.).

### **COVID-19 Regulations:**

In adherence with national COVID-19 regulations and current Massey University guidelines, please note the following:

- If you are positive for COVID-19, please do not attend the yoga classes until you are clear and negative for COVID-19.
- If you are feeling unwell, having cold/flu symptoms, it is up to you whether you would like to attend the yoga class or whether you would like to attend once you feel better.
- If you are feeling unwell during the yoga class, please be considerate of others and keep a safe distance from the other participants and yoga instructor if necessary.
- Please notify me, the researcher, if you are unable to attend a yoga class for any reason (e.g., sickness, emergencies, other commitments, etc.).

School of Psychology  
Massey University  
Private Bag 102-904  
North Shore  
Auckland 0745



COLLEGE OF  
HUMANITIES AND  
SOCIAL SCIENCES

**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 at any point (*within 6 weeks of research start date, data you have provided up until that time will be used in the research, but you may request to withdraw such data; if after 6 weeks of research start date, any data you have provided will be used in research, you may not request for withdrawal of data*);
- Ask any questions about the study at any time 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.

**Contact details:**

My primary supervisor is Dr Kathryn McGuigan, senior lecturer at Massey University (Albany campus). If you have any questions or enquiries, please do not hesitate to contact myself or Kathryn.

<b>Pretty Samudraningsih</b> <i>Student researcher</i>	<b>Phone:</b> [REDACTED] <b>Email:</b> <a href="mailto:pretty_sn11@hotmail.com">pretty_sn11@hotmail.com</a>
<b>Dr Kathryn McGuigan</b> <i>Supervisor &amp; lecturer</i>	<b>Email:</b> <a href="mailto:k.mcguigan@massey.ac.nz">k.mcguigan@massey.ac.nz</a>

**Support information:**

If you find the research distressing or uncomfortable, please seek your existing support services. It may also be good to speak with your GP or other medical professionals. Below are some resources you may contact or find useful:

- **Depression helpline:** 0800 111 757 or text 4202
- **Lifeline:** 0800 543 345 or text 4357
- **Samaritans:** 0800 726 666
- **Healthline:** 0800 611 116
- **Need to talk?** Call or text 1737
- **Mental Health Foundation website:** <https://mentalhealth.org.nz>

*This project has been reviewed and approved by the Massey University Human Ethics Qhu Matatika 1, Application OM1 23/10. If you have any concerns about the conduct of this research, please contact A/Prof Louise Brough, Chair, Massey University Human Ethics Qhu Matatika 1, telephone 06 356 9099 x 84575, email [humanethics1@massey.ac.nz](mailto:humanethics1@massey.ac.nz).*

*Note: Please ensure adherence with national COVID regulations (<https://covid19.govt.nz/>) and current Massey University guidelines. For supervisors: Refer to guidance in the Massey University Pandemic Plan (<https://masseyuni.sharepoint.com/sites/Coronavirus>). For students: Refer to [https://www.massey.ac.nz/massey/about-massey/news/advice-on-coronavirus-outbreak/advice-on-coronavirus-outbreak\\_home.cfm](https://www.massey.ac.nz/massey/about-massey/news/advice-on-coronavirus-outbreak/advice-on-coronavirus-outbreak_home.cfm).*

2. Yoga Instructor Information Sheet:

School of Psychology  
Massey University  
Private Bag 102-904  
North Shore  
Auckland 0745



COLLEGE OF  
HUMANITIES AND  
SOCIAL SCIENCES

***Endometriosis & Savasana: Exploring Pain Management for Endometriosis Through the Practice of Yoga***

**INFORMATION SHEET (yoga instructor)**

**Researcher introduction:**

Kia ora, thank you for your interest in this research project. My name is Pretty Samudraningsih and I am a student in the Master of Arts programme at Massey University, majoring in Psychology.

**Project description:**

The purpose of conducting this research is to investigate women's journeys with endometriosis, and how pain caused by endometriosis has affected them. This research will focus specifically on yoga as a pain management approach, with the aim to assess its effectiveness in reducing pain caused by endometriosis. The study will be following a maximum of 10 women who have endometriosis over the course of 12 weeks as they self-report each day in their journals of their pain levels, and practice yoga.

Participants will write in their self-report diaries every day for 12 weeks. They will write about their pain levels each day, as well as any additional information they may wish to add, such as any exercise they did that day, menstrual patterns, emotions, etc. After 4 weeks of starting, the participants will begin to attend 2x yoga classes each week, for the next 8 weeks. Each yoga session is to be 60 minutes long.

A qualified yoga instructor is needed to conduct these yoga sessions. The yoga instructor will need to be able to run these 60-minute yoga sessions 2x per week for 8 weeks. They must be qualified and comfortable in teaching a form of yoga that is suitable for beginners (e.g., Hatha yoga). The yoga instructor will be paid \$30 per session as a compensation for offering their time, skills and effort in this research.

**Selection criteria:**

- Qualified yoga instructor
- Must reside in Auckland, New Zealand.
- Must be available to coordinate 2x 60-minute sessions per week for 8 weeks (16 yoga sessions in total).
- Must be trained and comfortable in teaching a form of yoga that is suitable for beginners (e.g., Hatha yoga).

**Guidelines & confidentiality:**

This research is intended to be a positive experience for everyone involved (participants, yoga instructor, researcher), and hopefully those involved can finish the research and feel that their experience in the research has been valuable. The participants involved in the study will be women who come from different backgrounds, different endometriosis journeys, across all ages, and varying levels of physical abilities. It is important that the yoga instructor conducts the sessions in an ethical and sensitive manner, to ensure a safe, comfortable and amicable environment for the participants.

## Appendix D: PAR-Q Health Screening Questionnaire

### **Health Screening Questionnaire (for potential participants that are unsure about their fitness and/or physical condition)**

*When individuals contact me (the researcher) about their interest in participating in the research, I (the researcher) will call them to explain the research aims, procedures and selection criteria. I will then ask them the below questions from the PAR-Q, assessing their fitness. If they answer 'YES' to any of the below questions, I will ask them to first consult with their GP and obtain a signed note from their GP that they are fit enough to participate in the study.*

#### **Physical Activity Readiness Questionnaire (PAR-Q)**

##### **Tick yes or no**

- Has your doctor ever told you that you have a heart condition or high blood pressure?
- Do you feel pain in your chest at rest, during your daily activities of living OR when you do physical activity?
- Do you lose balance because of dizziness OR have you lost consciousness in the last 12 months? (please answer NO if your dizziness was associated with over-breathing, including during vigorous exercise)
- Have you ever been diagnosed with another chronic medical condition? (other than heart disease, high blood pressure, or endometriosis)
- Are you currently taking prescribed medication for a chronic medical condition, besides for your endometriosis?
- Do you currently have (or have had within the last 12 months) a bone, joint, or soft tissue (muscle, ligament or tendon) problem that could be made worse by becoming more physically active? (please answer NO if you had a problem in the past but it does not limit your current ability to be physically active)
- Has your doctor ever said that you should only do medically supervised exercise?

If answered YES to any of these questions, please see the GP and obtain a signed form to say you are fit to participate in the study.

The PAR-Q was developed to standardise activity screening for people aged 15-69. The PAR-Q will assess whether the individual needs to seek medical advice from a GP before starting physical activity or exercise. PAR-Q was created by the British Columbia Ministry of Health and had been endorsed by the American College of Sports Medicine. PAR-Q determines the safety of possible risks of exercising based on medical history.

**Appendix E: Consent Form**

1. Participant Consent Forms:

School of Psychology  
Massey University  
Private Bag 102-904  
North Shore



COLLEGE OF  
HUMANITIES AND  
SOCIAL SCIENCES

***Endometriosis & Savasana: Exploring Pain Management for Endometriosis Through the Practice of Yoga***

**PARTICIPANT CONSENT FORM – INDIVIDUAL**

- 1. I have read and I understand the ‘Information Sheet’.....
- 2. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction.....
- 3. I understand that I may withdraw from the study at any point throughout the 12 weeks.....
- 4. I understand that if I withdraw from the research within 6 weeks of the research start date, the information I provide until the withdrawal date will be used in the research. If I do not wish for the information to be included in the research, I understand that I have to contact the researcher and specify this. If I withdraw from the research after 6 weeks of the research start date, any information I provide up until the withdrawal date will be used in the research.....
- 5. I understand that once the transcripts of the interviews are sent to me, I have 2 weeks to read, respond and make any changes. If I do not respond after 2 weeks, I understand that the researcher will use the transcripts as they are.....
- 6. I understand that I may ask further questions at any time.....
- 7. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary.....

# ENDOMETRIOSIS & YOGA

School of Psychology  
Massey University  
Private Bag 102-904  
North Shore



COLLEGE OF  
HUMANITIES AND  
SOCIAL SCIENCES

- I agree/do not agree to the interviews being sound recorded.
- I wish/do not wish to have my recordings returned to me.
- I wish/do not wish to have my data stored in a secure Massey University data storage system.
- I agree to participate in this study under the conditions set out in the Information Sheet.

## **Declaration by Participant:**

I \_\_\_\_\_ [print full name] \_\_\_\_\_ hereby consent to take part in this study.

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Appendix F: Yoga Instructor Confidentiality Agreement and Behaviour Guideline**

1. Confidentiality Agreement:

School of Psychology  
Massey University  
Private Bag 102-904  
North Shore  
Auckland 0745



COLLEGE OF  
HUMANITIES AND  
SOCIAL SCIENCES

***Endometriosis & Savasana: Exploring Pain Management for Endometriosis  
Through the Practice of Yoga***

**CONFIDENTIALITY AGREEMENT**

I ..... (Full Name - printed)

agree to keep confidential all information concerning the project .....

.....

..... (Title of Project).

I agree to keep participants' information confidential and any information regarding their endometriosis journeys shared during the yoga class and/or conversations, confidential (e.g., participants' names).

I will not retain or copy any information involving the project.

**Signature:** ..... **Date:** .....

2. Behaviour Guideline:

**Behavioural & Codes of Conduct Guideline**

Thank you for your interest in getting involved with this research around endometriosis and yoga as a form of pain management. This research is intended to be a positive experience for all individuals involved- the participants, myself (researcher) and you, the yoga teacher. Participants will be coming into this research and practicing yoga from different physical ability levels, backgrounds, and experiences with endometriosis. To ensure a safe and comfortable space for all, please be mindful and sensitive of these differences across the participants. Below is a guideline that can be referred to in order to ensure the yoga classes are conducted following ethical practice and to ensure an amicable environment.

- The yoga instructor should act and treat the participants with respect.
- The yoga instructor should be sensitive towards the participants' physical abilities to practice yoga. Participants' abilities and pain levels are different across each individual and the yoga instructor should be patient and understanding about this.
- No offensive language to be used during the yoga classes.
- The yoga instructor will treat any information about the participants as confidential (e.g., name, endometriosis experience, etc.).
- If a participant is unable to do a pose because of any pain or discomfort, the yoga instructor is advised to amend the pose for the participant- they can alter the pose to make it easier and more comfortable for the participant. Otherwise, the participant shall be able to lie down or sit and continue when they can.
- Participants may take a break at any point, for as long as they need, if the yoga gets too much for them and/or their pain level.

I hope that everyone involved will have a positive experience throughout the duration of the research and finds that the techniques learned in the yoga classes have been beneficial for their endometriosis and everyday lives. I also hope that this experience will help people build social relationships and connect with each other such as through shared experiences and getting to know others' endometriosis journeys. Thank you again for dedicating your time and effort in this research, and thank you for sharing your skills to help women in dealing with endometriosis pain.

## Appendix G: Interview Guide & Safety Plan for Interviews

### 1. Interview Guide:

#### Interview Guide/Schedule

The initial meeting with individual participants will be semi-structured interviews, and more to get to know the participant's general details (e.g., age, ethnicity, stage of endometriosis, etc.), as well as their endometriosis journey. Details of the research, procedures and consent will also be discussed with the participants. Another instance where single semi-structured interviews will be held during the research is at the end of the intervention, at the end of the 12 weeks.

These interviews will be conducted in a semi-structured format. This means that the questions will not be strictly formal, but rather the questions and topics will be based around the participants' experiences and their responses. The order and context of the interviews will be more conversational. Below are some of the topics I will ask the participants during the initial meeting and at the post-test interview, along with some subtopics and questions I may ask.

#### **Initial meeting**

##### Introductions and admin:

- Introducing myself, asking the participant to introduce themselves.
- Advise them that the meeting will be audio recorded.

##### Getting to know participant and *whakawhanau* (relationship building):

- Ask participant to explain a little bit about themselves (e.g., what they do for a living, where they live in Auckland)
  - “What do you do for a living?”
  - “How did you hear about this research?”
- Share some information about myself
  - “I’m Indonesian but have been in New Zealand since I was 5”
  - Introducing why I chose to conduct this research and my experience with endometriosis.
- Ask them why they are interest in participating in the research
  - “What made you interested in getting to know more about this research and potentially participating?”

- Asking about their endometriosis journey- asking questions about subtopics they have mentioned, so more conversational

Project description:

- Summary of the research (e.g., aim, duration of project, procedures).
  - “The study will run for a total of 12 weeks, and you will be doing yoga 2x per week for 8 weeks.”
  - Give details about the use of self-report diaries and completing the pre-test, mid-test and post-test questionnaires.
  - Also mention that there will be semi-structured interviews at the end of the research,
    - “...similar to this, where I will ask you about your experience during the research, if you noticed anything different about your body or mental health, etc.”
  - “I hope that this time frame isn’t too long for you, however please note that should you decide to participate, you can also withdraw at any point”.
- State that participation will be voluntary, financial compensation of \$20 fuel voucher.
  - “If you would like to be a participant in the study, it will be voluntary. There will be \$20 fuel vouchers given to participants to thank them for their time, travel and effort in the research. I hope that the potential benefits that can come out of this research, such as improved mental and physical health, can draw you in to getting involved.
- Mention participant criteria:
  - “For this research, we have a selection criteria which you may have seen on the advertisement” (mention inclusion criteria)
  - “Because the research is incorporating some physical activity, which is yoga, there are some exclusion criteria, to ensure that we are not putting any participants at risk. For example, if you are pregnant or have a serious medical condition that you think may put you at risk by doing yoga. Would any of these apply to you?”
  - Are you able to bring your own yoga mat?

Debriefing:

- “I’ve brought along with me an information sheet that covers all the details about the research, as well as a consent form to complete should you choose that you want to participate in the research”
- Bringing the conversation to a natural end
  - “Please feel free to contact me if you have any other questions or enquiries about anything”
  - “Is there anything else you wanted to mention?”
- “Thank you so much for taking the time to meet with me today, it’s been really nice to meet with you and getting to know more about your background and interest in the research”
- Provide support sources
  - “We’ve discussed some pretty heavy stuff today, if you’re ever wondering about any support services for mental health or endometriosis support groups, I can send you through a few of them if you like? Sometimes it’s good to even just read about some information on their websites”
- “Thank you again for meeting with me today”
- Bring back conversation to present
  - “What are you doing for the rest of the day?”
  - “I’ll be sure to get in touch with you

**Post-test semi-structured interviews**

Greetings and admin:

- “Hi \_\_\_\_\_, good to see you again. How have you been?”
- Ask them what they thought about going to the last yoga session.
- “Thank you very much again for getting involved the research, I hope that it has been beneficial for you also, and that you got experience and get a better insight into yoga”
- Advise that the interview will be audio recorded.
- “I’ll be recording our interview today, will that be okay with you? If there are any questions you do not feel comfortable answering or topics you want to skip, please let me know. And please also let me know if you feel uncomfortable in any way and want to stop the recording”

Getting to know their yoga experience in the research:

- “So first of all, how did you find everything? How did the research go for you and what was your experience like?”
- “Before this research, had you done yoga before?”
  - “If not, how did you find the yoga sessions and how did you feel?”
  - “If you have done yoga before, did you experience anything different with these yoga sessions than previous ones? Such as were there any techniques or poses that were new to you?”
- “Were there any moments you enjoyed most or didn’t particularly like the most?”
- “Did you find that the yoga sessions were what you expected?”
- “Did you feel any changes in throughout the research? Physical, mental health, pain?”
- “Getting more familiar with the yoga poses as the sessions go by, did you implement any of them outside of the classes? For example if you were feeling any pain at home?”

Physical and emotional wellbeing before the research:

- Get a sense of how the participants’ wellbeing were prior to research.
- “Can you tell me a little bit about your physical and mental health before joining the research and what it means to you?”
- “Would you say that your physical and mental health were largely influenced by your endometriosis symptoms and the pain you were feeling?”
- Ask them about medication and treatment
  - “How did you feel about the medication or treatments for your endometriosis before?”
  - “Had you tried an alternative form of pain management before, such as yoga? Or thought about doing it?”

Takeaway from the research:

- Ask about how the participants feel that it is the end of the research now
- “Having done the research now, was it what you expected? How similar or different was it to what you thought it would be?”
- Ask them if they feel they have learned anything useful in the research

- “Are there any new things that you learned whilst participating in this research?”
- “Are there any takeaways from the research that you may implement more so in your everyday life now?”
- “Overall, would you say you noticed any changes or not in your pain levels? Did they reduce, stay the same, get worse, once starting the yoga?”

### Privacy and data management:

- Inform the participants of the data management and privacy, how their information and identities will be kept private
  - “In terms of privacy and finalising the data I’ve collected in this research, I will transcribe our interviews into written form. I’ll ask you to look over them and you can make any changes if you like”.
  - “If I wanted to include a quote from you that was said during our meetings, I will ask for your permission first to include it in the data report, and will use a pseudonym for you or keep it nameless”.
- Ask if they would like a summary of the findings
  - “Would you like a copy of the summary of the findings?”

### Debriefing:

- Bringing conversation to a natural end
  - “I see that we’re close to running out of time for our meeting. Is there anything you wanted to mention?”
  - “Thank you very much again for your involvement and participating in this research for the last 3 months and dedicating your time. I hope that you’ve gotten some insightful information along the way”
- Provide support services
  - “Throughout the research and during our interviews, speaking about your experiences with endometriosis can be tough. If you like, I can send you through some support services for mental health and endometriosis through an email?”
- “Thank you so much again for participating in the research and meeting with me today.

- “Please do not hesitate to contact me or my supervisor if you have any other questions or enquiries about the research”
- “What are your plans for the rest of the day?”

2. Safety Plan for Interviews:

**Safety plan for interviews**

The following safety practices for this research concern the physical and psychological safety of both participants and researcher during the interview processes. This includes the initial meeting with each participant prior to starting the research, and the semi-structured interviews with each participant once the mediation is completed and research is concluding. The practices here can be applied to any environmental setting (e.g., participant's home, public library).

Before the initial meeting & post-test interview:

- 1) When organising the interview with participants (e.g. phone call or email), I will advise that they may bring a support person or item/s and ask if they would like to bring someone to the initial meeting and/or interview.
- 2) I will ask participants for the contact details of a chosen person who may be aware of their participation in the interview. If the participant does not want anyone knowing about their participation in the interview, emergency services for whatever reason will be used.
- 3) Notify supervisor (Dr Kathryn McGuigan) of time and location of each interview, and approximately how long it will take.
- 4) Just before the interview I will text my supervisor and after the interview finishes I will confirm with my supervisor that the interview has finished.

During the initial meeting & post-test interview:

- 5) Have phone available (but on silent) to make any calls in relation to the physical or psychological safety of the participant or myself. Dr Kathryn McGuigan will be available to respond to any needed phone calls.
- 6) Take note of nearest exit and sit towards nearest exit.
- 7) Occasional check in with participant during the interview, asking how they are feeling and whether they would like a break.
- 8) Breaks will be offered when decidedly appropriate (i.e., not interrupting participants when they are sharing their stories) and when participants request a break.
- 9) Where participants appear distressed, and when decidedly appropriate (i.e., not interrupting participants they are sharing their stories), I will check in and ask if they would like a break. Participants will be reminded that they do not need to answer questions they do not feel comfortable answering.

After the initial meeting & post-test interview:

- 10) At the end of each interview, I will check in with participants and how they are feeling. I will offer to email them contact details of support and emergency services. I will also discuss with them what they have planned for the remainder of the day to flow the communication back to a more conversational style.
- 11) Notify supervisor of the interview finishing.

- 12) If any topics discussed during interviews were distressing for me, I will contact my supervisor or any support services.

Steps that will be taken to ensure the researcher's safety if interviews are conducted in participants' homes:

- 1) Before going in to the interview in the participant's home, I will inform Dr Kathryn McGuigan that I am meeting this participant, the time I am meeting them, and approximately how long the meeting will take, estimated finish time.
- 2) I will take note of the nearest exits, sitting closest to the exit.
- 3) I will have a phone available (on silent) in case of needing to make any phone calls. I will message Dr Kathryn McGuigan when I am finished with the interview, so that she knows I am safe.

**Appendix H: Journal Formats**

1. Format of Journal Page for the first four weeks and on the days there were no yoga classes:

On average, how much pain did you experience today?

A horizontal line with vertical tick marks at each integer from 0 to 10. Below the line, the numbers 0 through 10 are printed. Under the number 0, the text "No pain" is written. Under the number 4, the text "Moderate pain" is written. Under the number 10, the text "Worst possible pain" is written.

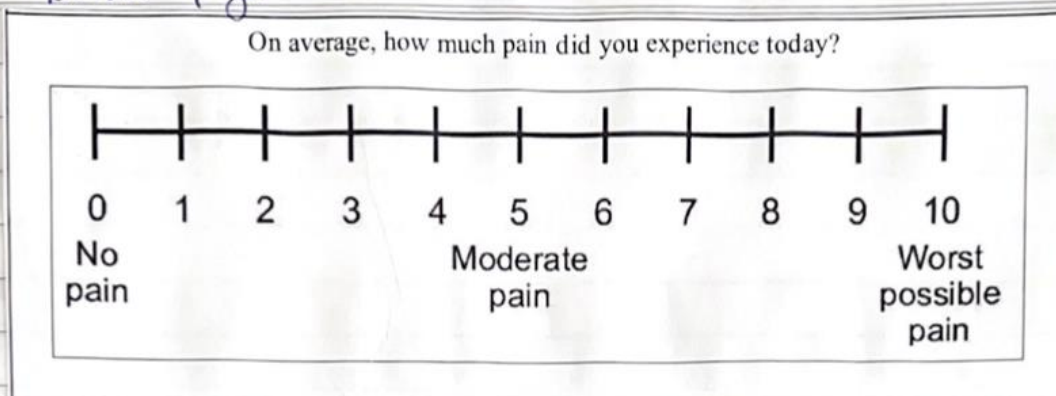
0 1 2 3 4 5 6 7 8 9 10

No pain Moderate pain Worst possible pain

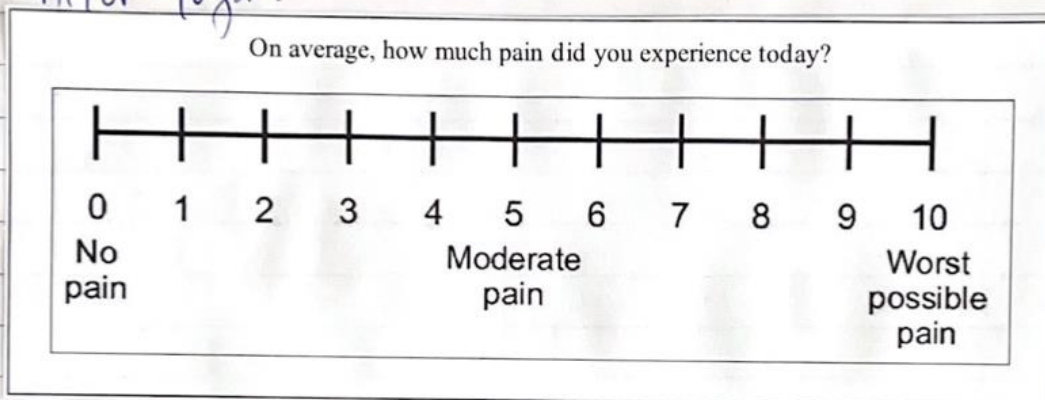
# ENDOMETRIOSIS & YOGA

## 2. Format of Journal Page On Yoga Days:

Before yoga:



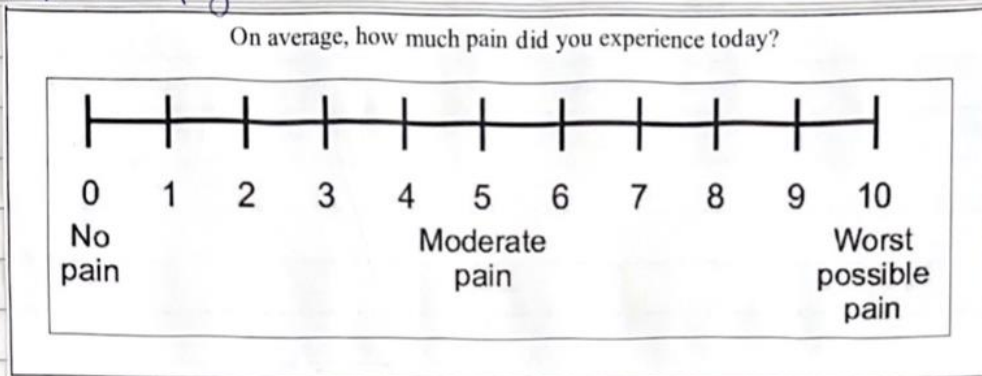
After yoga:



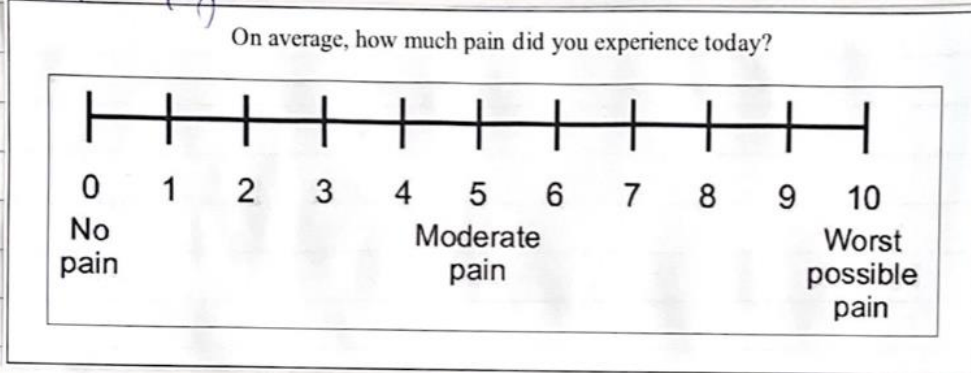
ENDOMETRIOSIS & YOGA

3. Format of Journal Page 6 Weeks Into the Research- On the Day Participants Had to Complete the Short 5-Question Endometriosis Health Questionnaire:

Before yoga:



After yoga:



In the last 4 weeks, how often, because of your endometriosis, have you...

	Never	Rarely	Sometimes	Often	Always
Felt unable to cope with the pain?					
Felt that your symptoms are preventing you from doing the things you want to do?					
Felt depressed?					
Felt that your symptoms affected your confidence?					
Felt anxious about having intercourse because of the pain?					

**Appendix I: Endometriosis Health Questionnaires**

1. Endometriosis Questionnaire Completed At the Beginning and End of Research (25-Questions):

In the last 4 weeks, how often, because of your endometriosis, have you...

	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
<b>Not been able to do jobs around the house because of the pain?</b>					
<b>Not been able to do any exercise or physical activities because of the pain?</b>					
<b>Not been able to attend social gatherings/events because of the pain?</b>					
<b>Found it difficult to concentrate on tasks because of the pain?</b>					
<b>Had difficulty walking because of the pain?</b>					
<b>Had difficulty sleeping or get a good night's sleep because of the pain?</b>					
<b>Had to lie down/rest because of the pain?</b>					
<b>Had to take painkillers to relieve your pain?</b>					
<b>Felt that you could not cope with the pain?</b>					
<b>Been unable to eat because of the pain?</b>					
<b>Felt your symptoms prevented you from doing the things you wanted to do?</b>					

<b>Felt hopeless in enduring the pain?</b>					
<b>Felt that your symptoms are controlling your life?</b>					
<b>Felt that your symptoms are impacting your quality of life?</b>					
<b>Felt unable to carry out your core responsibilities due to the pain?</b>					
<b>Felt you were overly sensitive/moody?</b>					
<b>Felt depressed?</b>					
<b>Felt alone/isolated?</b>					
<b>Felt irritable?</b>					
<b>Felt that others believe you are complaining too much about the pain?</b>					
<b>Felt that your symptoms affected your confidence?</b>					
<b>Felt uncomfortable with your appearance or in your own skin?</b>					
<b>Believed that you cannot present yourself the way you want to?</b>					
<b>Experienced pain during or after intercourse?</b>					
<b>Avoided having intercourse because of the pain?</b>					

ENDOMETRIOSIS & YOGA

2. Endometriosis Questionnaire Completed 6-Weeks (Midway) Into the Research (5-Questions):

In the last 4 weeks, how often, because of your endometriosis, have you...

	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
<b>Felt unable to cope with the pain?</b>					
<b>Felt that your symptoms are preventing you from doing the things you want to do?</b>					
<b>Felt depressed?</b>					
<b>Felt that your symptoms affected your confidence?</b>					
<b>Felt anxious about having intercourse because of the pain?</b>					

**Appendix J: Themes and Subthemes Found Within Participants’ Datasets.**

Table of Themes and Subthemes of Participants’ Data (Created During Brainstorming and RTA):

<b>THEME</b>	<b>SUBTHEMES</b>	<b>SUB-SUB THEMES</b>	<b>SUB-SUB-SUB THEMES</b>
1. Experiencing endometriosis pain	<p>a. Pain and diagnosis journey</p> <p>b. Control and powerlessness</p> <p>c. Intersection of mental and physical wellbeing</p> <p>d. Pain and QOL</p>	<p>a.a. Pain dismissed</p> <p>b.a. “Tolerating”</p> <p>b.b. Sense of hopelessness</p> <p>b.c. Shaping life around endometriosis</p> <p>c.a. Shame</p> <p>c.b. Guilt</p> <p>c.c. Anxiety</p> <p>c.d. Fear</p> <p>c.e. Self-doubt</p> <p>c.f. Frustration</p> <p>c.g. Stress</p> <p>c.h. Mental and physical fatigue</p> <p>c.i. Sleep quality</p> <p>d.a. Effects on dating</p> <p>d.b. Intimacy</p>	<p>a.a.a. Lack of knowledge by medical professionals</p> <p>a.a.b. Experiences of misogyny and sexism</p> <p>a.a.c. Delay in diagnosis</p> <p>a.a.d. Distrust in health care system</p> <p>d.b.a. Self-intimacy</p>

ENDOMETRIOSIS & YOGA

		<p>d.c. Employment</p> <p>d.d. Fertility</p> <p>d.e. Emotional wellbeing</p> <p>d.f. Self-image</p>	d.b.b. Intimacy with a partner
--	--	---	--------------------------------

THEME	SUB THEMES	SUB-SUB THEMES	SUB-SUB-SUB THEMES
2. Treating endo pain	<p>a. Medical options</p> <p>b. Lack of options</p> <p>c. Self-management</p>	<p>a.a. Hormonal medication</p> <p>a.b. Painkillers</p> <p>a.c. Surgery</p> <p>a.d. Nerve restoration</p> <p>b.a. Disbelief by doctors</p> <p>b.b. "Normal" period pain</p> <p>b.c. Cause of pain and symptoms diverted to other non-endo conditions</p> <p>c.a. Diet</p> <p>c.b. Heat</p> <p>c.c. Relaxation</p>	<p>a.b.a. Prescribed</p> <p>a.b.b. Over-the-counter</p> <p>b.b.a. Drama queens</p> <p>b.b.b. Low pain tolerance</p> <p>b.c.a. Diet</p> <p>b.c.b. Depression</p> <p>b.c.c. Stress</p>

ENDOMETRIOSIS & YOGA

		<p>c.d. Sleep</p> <p>c.e. Yoga</p> <p>c.f. Light physical activity</p>	
--	--	--	--

THEME	SUB THEMES	SUB-SUB THEMES	SUB-SUB-SUB THEMES
3. Yoga and QOL	<p>a. Mental wellbeing</p> <p>b. Self-image</p> <p>c. Social support</p>		

THEME	SUB THEMES	SUB-SUB THEMES	SUB-SUB-SUB THEMES
4. Benefits of yoga on body	<p>a. Flexibility</p> <p>b. Muscle toning</p> <p>c. Stretching</p> <p>d. Strengthening</p> <p>e. Challenging</p> <p>f. Short-term pain relief</p>		

THEME	SUB THEMES	SUB-SUB THEMES	SUB-SUB-SUB THEMES
5. Benefits of yoga on mental health	<p>a. Confidence</p> <p>b. Control</p> <p>c. Independence</p>		

ENDOMETRIOSIS & YOGA

THEME	SUB THEMES	SUB-SUB THEMES	SUB-SUB-SUB THEMES
<p>6. Yoga and perception of pain</p>	<p>a. Participants' reflections on their yoga experience and endo</p> <p>b. Effect on perceptions of endo-associated pain</p>	<p>a.a. Did not notice change in endo-associated pain</p> <p>a.b. Slight improvement in perceived pain (short-term and inconsistent)</p> <p>a.c. Felt pain during and/or immediately after yoga (short-term)</p> <p>a.d. Connection to body and understanding its abilities and limits</p> <p>a.e. Increased awareness in mental and physical wellbeing</p> <p>a.f. Social support</p> <p>a.g. Psychological impact</p> <p>b.a. Helped</p> <p>b.b. Didn't help</p>	<p>a.a.a. Too many extraneous variables to identify significant change</p> <p>a.d.a. Body positivity</p> <p>a.d.b. Self-esteem</p> <p>a.e.a. Improved health and lifestyle</p> <p>a.g.a. Enjoyment</p> <p>a.g.b. Relaxation helped with short-term pain relief</p> <p>a.g.c. Improved mood</p>